# Am I sick enough?

## Exploring the narratives of women who have received nasogastric tubes as part of treatment for anorexia nervosa

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# Abstract

Objective: Despite nasogastric tubes frequently being used in inpatient facilities as part of treatment for anorexia nervosa, there is currently only two studies that explore the lived experience of this treatment. This research explores in depth women's experiences of nasogastric feeding for anorexia nervosa. In doing so there were two research questions; what was the experience of having a nasogastric tube and how did this change their relationship with anorexia nervosa.

Method: Using narrative interview methods seven women were interviewed to explore their experience with nasogastric tubes in the context of treatment for anorexia nervosa. These women had received treatment in either New Zealand, Australia or England. The interviews were then transcribed and analysed using narrative analysis. The analysis was guided by a social constructionism epistemology and utilised Goffman, Frank and Foucauldian theory.

Findings: Five main narrative points resulted from the analysis. These five narrative points focused on the insertion process, the question of am I sick enough, types of nasogastric feeds, living with the nasogastric tube and resisting the nasogastric tube. Each narrative point explored how these experiences influenced their treatment experience.

Conclusion: Nasogastric tubes are a complex part of treatment for anorexia nervosa and while there is the ontological reality professionals face as there are serious consequences as a result of starvation, the use of nasogastric tubes is complex and extends beyond concerns with weight gain. Participants described an internal battle where they are entangled in a series of power dynamics around how to respond in inpatient treatment, where the environment to receive treatment is iatrogenic in nature. Consequently, when they get into treatment, they find they are put in a position where if they are treatment

adhering and accept the nasogastric tube, they worry staff will believe something is wrong with them and they are not sick enough. Where if they resist, they are then met with threats and often punishments that are experienced as traumatic. The nasogastric tube resultingly becomes a symboliser of the idea of being sick enough.

# Introduction

Within this thesis I set out with one aim, to provide women who have received nasogastric feeding due to anorexia nervosa (AN) a place and space where they could be heard. The nasogastric tube (NGT) is a complex part of eating disorder treatment; an NGT in presentation is a visible marker of an illness. It remains on the side of an individual's face, tucks behind their ear and speaks of an experience of a body being 'mismanaged' without the individual having the opportunity to speak their own words. To some it is a romanticised piece of equipment, to others a validator of their illness, to others it is a relief as they are no longer responsible for eating. Along with this, the NGT is illustrative of the power dynamic one experiences when they enter treatment, it conveys the medical gaze, control, objectification and alienation. The NGT represents an internal dialect held by the individual, an internal fight filled with complexities and often disregarded or unacknowledged within a medical capacity. A NGT, while a piece of flexible plastic, illuminates the complexities and contradictions between AN, treatment and the lived experience.

Over the course of my study I interviewed seven women who had received nasogastric feeding as part of treatment for AN from three different countries. Each of these women's stories illuminated not only the complexity and confusion that exists around having experienced nasogastric feeding, but the longer-term implications of having received a tube. Their accounts carried conflicting emotions, elements of trauma, sadness and at times a sense of loss around their experiences.

As the aim of my thesis was to provide women with a place where they could share their experience, I employed qualitative methods, asking each woman to tell me their story of having a NGT. My aim was to not to shape the research by my own questions, but rather

to ask them an open-ended question where I asked if they could tell me about their experience with having a NGT, the point at which they started their narrative depended on the individual and ranged from the development of their AN, to the few moments before the NGT was inserted. For most of the women involved in my project, this was one of the very few times they had spoken their story.

In asking this research, I had two research questions:

- Firstly, what was the experience of having a NGT like for them
- Secondly, how did having a NGT change their relationship with AN

What came from these two research questions were rich narratives, illustrating strength, resilience and stories of survival.

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*"You Set the Tone, Carter"*

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# Chapter One

# The history of AN:
# A socially constructed phenomena?

AN today is dominated by a biomedical discourse. Drawing on this discourse, the individual most likely to experience AN is commonly perceived as a young emaciated white woman. Symptoms of anorexia are constructed as significantly underweight, having a dispositional fear of gaining weight, mitigating any attempt of weight gain and lacking insight into the severity of her illness (American Psychiatric Association, 2013). AN is understood as a modern illness, that derives from a sense of vanity compounded by a current cultural discourse emphasizing the notion '*thin is in*'. However, AN is a complex phenomenon with a longstanding history. This chapter traces the genealogy of AN, examining the sociocultural, historical and political influences, and situates AN as a socially constructed phenomena, rather than a dis-order[1] that maintains a strict pathology.

Through the utilisation of Foucault's genealogical practices (1972), it allows for the exploration of how a specific narrative has come to be by examining the political, moral, economic, cultural and social institutions that define what is assumed as acceptable knowledge (Anaïs, 2013). By taking a genealogical approach to the history of AN, rather than an archaeological approach, it allows for the examination of how self-starvation has been conceptualised and the discursive practices used to understand such behaviour.

## Early conceptualizations of self-starvation

Self-starvation has been documented in historical texts dating back to as early as the 14th century with women placed at the centre of these acts (Brumberg, 2000). Early accounts of AN were caught up with a religious discourse, with assumptions young women engaged in self-starvation in attempt to draw closer to God, while simultaneously starving away from the terror of hell awaits gluttons (Bell, 1987). During this time, the act of self-starvation was termed Holy-anorexia. It has been a longstanding debate amongst theorists e.g. Brumberg (2000) & Bell (1987) whether acts of religious self-starvation can be comparable to modern day AN. Here it is the use of religious discursive practices that framed Holy-anorexia and how this has influenced today's understanding of modern AN that is of interest.

During the 14th century in western world societies, the role women took in society was largely governed by the church. There were social expectations that women take on the role of a submissive housewife with little authority over themselves or society (Bell, 1987). The alternative to marriage and heterosexual servitude was to enter the convent. Becoming a nun provided women with the possibility to explore the idea of self-sufficiency and autonomy rather than engaging in the destiny that was "functionary of man and his culture" (Bell, 1987 p. 55). Bell (1987) suggests the convent offered women a chance to escape traditional roles as wife and mother allowing space for them to explore themselves whilst remaining well positioned in society.

Despite the convent allowing for a sense of self-sufficiency and autonomy from the role of a submissive housewife, women's position in society was regulated by the Christian understanding of monism between the soul and the body. This idea of monism was used as a regulatory method in society for controlling the body, where the idea was for an individual to renounce oneself in order to become closer to their soul, thus leading to God;

this was typically done through religious fasting (Appendix A) (Griffin & Berry, 2003). However, women who starved themselves rather than engaging in religious fasting often faced persecution as they were suspected of hosting demonic positions. Self-starvation was met with great disapproval from the clergy as those with Holy-anorexia often reported having a personal relationship with God, which threatened the position of the male clergy within the church and challenged how society perceived women's role within the church. Bell (1987) theorised Holy-anorexia as a representation of the struggle felt by women in a patriarchal society at that time. These ideas illustrate how religion had originally acted as a way of constructing the female body and the impact the church had, which was directed by males' influence regarding how females' bodies were understood.

Though we have largely abandoned religious discourses in today's context, there are several ways Holy-anorexia has contributed to the way we understand modern day anorexia. As in this specific time monism guided the body and how one acted in society, consequently, gluttony was viewed as a way of turning away from God. This in turn reflected the idea of food consumption relating to temptation, sin and guilt, while abstinence from food was tied to this idea of purity (Griffin & Berry, 2003). As society has evolved, though we no longer contribute eating or weight as being a pathway to hell, we still uphold this idea of food and weight being tied to morality and purity.

## The development of a diagnosis

In the 17th century, the western world moved away from the idea of monism where it was understood the soul and body existed as one and instead society started to understand the body and mind as existing in two different entities. This idea is regarded as Cartesian dualism (Metha, 2011). As society adapted this idea of Cartesian dualism, it moved away from the religious underpinnings which governed knowledge and society and instead moved to those in the medical profession governing knowledge. Therefore, our

understanding of how the body is constructed changed (Metha, 2011). Consequently, as the body was understood through a different perspective, the Holy from Holy-anorexia was dropped.

In 1873 two independent physicians Charles Lasègue and William Gull both published papers that systematically reported the symptoms of what would form the basis of modern-day AN. Both papers depicted the same set of symptoms; emaciation, amenorrhea, body mass loss, fatigue, slower breathing, lower pulse rate and a fall in body temperature (Niedzielski et al., 2017). While Gull and Lasègue both published papers mentioning a similar set of symptoms, they coined the term differently and approached their observations from different orientations.

Gull adopted the term anorexia, which was already familiar to the medical community and added the word nervosa. The word nervosa had historically been linked to hysteria and being neurotic in nature and therefore the term reflected the idea that individual's had a lack of appetite due to a nervous or neurotic state (Simonovic et al., 2015). Having a term linked to hysteria functions as a way of gendering AN. Women were perceived in society as being uncontrollable, unstable and experiencing somatic symptoms relating to a sense of madness. The term hysteria speaks of how women were perceived in society when their bodies are no longer considered docile (Foucault,1977). While the term hysteria has often been viewed as reflecting a sense of embodied patriarchal oppression, second wave feminists have reclaimed this term, reflecting the term could be viewed as a "protolanguage, communicating through the body messages that cannot be verbalized" (Devereux, 2014, p. 21).

In contrast to Gull, Lasègue reported the symptomology under the term anorexie hysterique and provided a more in-depth trajectory of those with AN linked to

physiological consequences, Lasègue positioned his findings from psychological origins and was the first to construct AN as a mental illness, rather than a physical one (Soh et al., 2010). Lasègue's definition reflected Victorian society's patriarchal understandings of women. Anorexie hysterique as a condition reflected women's natural emotional and unstable state and was considered representative of a failure to acculturate to the expected marital and domestic roles (Hepworth, 1999).

The 19th century adoption of the term of AN contributed to the development of the medical gaze and strongly positioned AN within a medical discourse. The initial publication of Gull's articles depicted women with AN appearing with sunken in cheeks, images transitioned to portray the anorexic body by showing gaunt torsos and transitioning to naked, sunken in bodies by the end of the century (O'Connor, 1995). The act of including these photographs allowed for medical professionals to view the emaciated body as something in which it could control through refeeding, with images depicting emaciation at its most naked of states, then comparing it with an image of the same girl who was depicted in a healthy state. Smith (1990) argues before and after images contain 'the gap for desire created by the deficiency of the present and actual in comparison with the idealist of the image now represented as an objective' (p. 190) The use of comparative images illustrated two points to the medical community: firstly, as stated by O'Connor (1995, p.542), "the pictures make up an evolving discourse on the physician's power over the anorexic body, silently asserting his ability to reform an aberrant physique according to an implicit ideal of female appearance". This perspective of the medical gaze of AN reflects the transformative practice of Foucault's (1977) idea of the docile body, where the body was once initially a protesting body reflecting a capacity in which it is denying what is considered as normative within society. Where the second image of the restored healthy body represents that through the medicalisation, the

body has been regulated and normalised in such a way it now reflects a healthy body in society (Mills et al., 2010).

## AN in the 20th century

During the 20th century various theorists attempted to understand AN outside of medical discourse and instead situate it within the realm of mental illness. Employing a psychological discourse was an attempt to move away from a medical discourse and provide explanation for why an individual may engage in self-starvation, however, ultimately it resulted in further embedding gendered understandings of AN.

Freud postulated that AN was the result of the underlying desire of a female to be male (Perlick & Silverstein, 1994) and engaging in self-starvation allowed her body to remain androgynous, as she did not develop curves, breasts or a menstrual cycle. The effects of self-starvation allowed her to deny the possibility of being viewed as a woman and thus sexualized. While Freud's perspective is often disregarded regarding his contribution to our understanding of AN, his thinking alludes to the gender-politics that are intertwined within society and traditional constructions of gender.

From the 1920s until the 1940s, medicines interest in AN was abandoned, but at the end of the 1940s and start of 1950s psychoanalytic theories of AN re-emerged. Dissimilar to the early 19th-century psychoanalytic interpretation of AN, 1940s psychoanalytic interpretations proposed individuals with AN were attempting to shield themselves against fantasies of oral impregnation, alternatively succumbing to deviant promiscuous fantasies (Gordon, 2000).

By 1952 the first edition of the Diagnostic Statistical Manual was printed (DSM-I) alongside the sixth edition of the International Classification of Diseases (ICD-6). Both

the DSM-I and ICD-6 included AN within their systems. The inclusion in both the DSM-I and the ICD-6 worked to confirm and reaffirm AN firmly in a biomedical discourse. As the symptomology of AN has been influenced by the historical understanding of AN, which is through a biomedical lens. The biomedical model is the dominant way in which health is socially understood in the western world, creating powerful ways of governing what knowledge is legitimised through societal power structures and what is sustained through social patterns (Burr, 2015). The legitimizing of knowledge therefore has implications for those who do not abide by what society and the medical profession has constructed as normal and, those that do not align with this idea of normal therefore become an issue of abnormality, personal deficit and deviance (Burr, 2015).

## Diagnostical and Statistical Manual

Since the original 1952 publication, the way in which AN was categorised within the DSM has changed but the symptomology remains largely the same (see Appendix B). The third publication of the DSM was particularly prominent in how we understand AN today. Bruch (1973) postulated that AN can be broken down into two types [primary and secondary AN]. Within the primary criterion, those with AN were described as having a distorted body image that is accompanied by a misplaced belief that they were fat (Gordon, 2000) This idea was specifically potent in how AN has been classified, as this was the first time this idea linked those with AN with a fear of being fat. Consequently, when the DSM-III was published in 1980 the criteria for AN changed, reflecting an emphasis on body and weight, rather than self-starvation being a psychological consequence of a physical origin. Subsequently the current and fifth publication saw a change in the diagnostic criteria for AN as being more inclusive, with the removal of amenorrhea and an underweight body mass index (BMI) (Appendix B) (Call et al., 2013).

In contrast to primary AN Bruch (1973) outlined secondary AN. This refers to other forms of psychogenic malnutrition or starvation, which is seen in individuals with depression, delusions, food phobia and hysterical vomiting (Habermas, 2015). Though the DSM cements AN as deriving from a biomedical discourse, Bruch (1973) distinguishing between primary AN and secondary AN, illustrates how the 1960's-1980's medicine shifted from a biomedical discourse and adapted the biopsychosocial model (Farre & Rapley, 2017). This adaption of the biopsychosocial model in medicine resulted in further entanglement of biomedical discourse and psychological discourse. Consequently, while Bruch (1973) definition of secondary AN, reflects what seems to be a psychological discourse of AN, it ultimately rests on a biopsychosocial framework and reflects the critique of Armstrong (1987, as cited in Rohleder, 2012, p.22).as the biopsychosocial model "remains essentially the biomedical model with the theoretical underpinnings of the social and psychological factors not being properly worked out".

While the DSM provides a stringent criterion that outlines the symptomology that reflects what we have constructed as a dis-order known as AN, there are several critiques to be made about the DSM and the impacts that this has on those with the reflected symptomology. As the DSM is reliant on the biomedical perspective to maintain its position of 'legitimacy' and authority (Lafrance & McKenzie-Mohr, 2013) the one mental illness is conceptualised is within a reductionist perspective. A reductionist perspective aims to reduce symptomology back to biological and neurological causes, this therefore means AN within the DSM is presented as a disease, rather than a socially constructed set of symptoms (Schaffner, 2013). The sharp boundaries in the criterion uses a specific set of criteria to determine who meets the criteria and who does not. For example, the first criteria states "restriction of food intake leading to weight loss or failure to gain weight resulting in a significantly low body weight, of what would be expected for someone's

age, sex and height" (American Psychiatric Association, 2013). Having such stringent criterion that is based on biological properties rather than focusing on the individual's behaviour and distress is problematic as it creates a discourse where those within a place of power (such as a clinician with diagnostic rights) focus on weight, rather than understanding AN through a biological sociological, historical and contextual lens that is unique to the person (Schaffner, 2013). Therefore, the use of such a criterion contributes to the power differentials that occur with accessing treatment, such as who has the right to access treatment and whose experiences are valid. This becomes particularly prominent when examining the lived treatment experience of AN, where individuals have been unable to access treatment for not being 'sick enough' (de la Rie et al., 2006; Rance et al., 2017).

Constructions of AN in the DSM fall into the idea that the body is something which can be controlled or regulated through mechanisms in society designed to bring about normality, which is constructed by those in positions of power such as the biomedical discourse. Bodies that do not meet this idea of normality are viewed as lesser and often are subjected to pathologizing and subordination in attempt to configure the body to align with naturalistic views (Shilling, 2012). The DSM therefore acts to configure the body to re-align with what is considered a normal body in society at the time.

Though the DSM provides categorisation of the symptomology of AN, it perpetuates the idea that the body abides to the rules of Cartesian dualism, which is further legitimised by those who hold power and who reproduce this idea to the greater society. As opposed to the position that the body is something that is socially constructed that can hold duality; the social body constraining the physical body (Synnott & Howes, 1992). The body is not a set of single biological functions or genes, rather the body is a social construct mirroring the social systems from which it derived from (Shilling, 2012). The way in which the

body is understood is dependent upon the time in which it exists, the legislations that govern society and the accepted cultural underpinnings all contributing to what is considered normative. Where specific groups in society regulates (e.g. medical, religious, political groups) what is viewed as accepted, thus the body is socially constructed acting as a metaphor for the time we exist. Therefore, applying this perspective to AN, rather than abiding to a stringent set of pathology. AN is expressive of a complex set of socio-political issues that are embedded and pervasive in society (Malson and Ussher, 1996).

## AN 1960s onwards

Understandings of the body as socially constructed coincided in the 1960's and 1970's with the occurrence of the second wave of feminism. During this time women's rights and taking control of their life and bodies were at the forefront of the social movement (Gagliardi, 2018). Consequently, the way women were presented in society changed drastically. This section will discuss the impact the second wave of feminism had on fashion, sexuality and diet culture and how this shaped contemporary understanding of AN.

### *Fashion and sexuality*

Women had long been perceived as being a sexual object and objectified, however, in the media and the public, females were presented somewhat conservatively prior to the 1960's. The emergence of the second wave of feminism encouraged women to take control and redefine themselves as someone with needs and desires that exist outside of pleasing a male (Baumeister & Twenge, 2002).

The female body, influenced by cultural factors of the time, changed the idea of the ideal women figure from being an hourglass figure to the new ideal, the twig. This new ideal figure was influenced by adolescent model Twiggy (Gordon, 2000; Orbach, 1986).

Along with the new ideal and newfound sexual freedom experienced by women, the way women were depicted in the media changed.

The focus was no longer centred on what clothed the body, but the naked body itself, exposing one's supposed flaws (Seid, 1994). By the 1980s, fashion focused on miniskirts, thigh-high boots, crop tops and the use of shaping garments. Alongside this sat a growing fitness industry with leotards and leggings encapsulating the 'thin ideal' and ensuring the body was on display for society to see (Gordon, 2000). The way that the body was positioned was now one that could not be hidden or altered by corsets or body wear to meet societal standards, but rather, the body was now on display.

Through the use of media, clothing, celebrities and in conjunction with medical professionals, the 'thin ideal' was legitimised within society for what a normal body should look like. The thin ideal incorporates western ideas of individualism and suggests that a thin body is one that holds success, purity and morality while a body that does not meet such status is viewed as a personal failure, weak-willed and, immoral (Klaczynski et al., 2004) This sentiment reflects a similar notion to how the female body was perceived during the 14$^{th}$ century when holy-anorexia was prominent. Seid (1994) reports how physicians further legitimised the thin ideal, claiming that you could not be too thin, thus physicians held this dual contradictory idea, where the body couldn't be too thin, while simultaneously pathologizing extreme thinness as AN. Within this perspective, those whose bodies did not meet society standards were viewed as having a mismanaged body, one in which needed to be corrected through diet and restriction or alternatively, refeeding.

It is interesting, and at times antithetical, that during the second wave of feminism women were demanding to be heard and valued as equal to men, but simultaneously were, in the

name of engaging with the feminist demands of that time, attempting to shrink ourselves to fit with media and societies' representations of women. It is as if, our voices alone, nor the work we perform, could be enough, and rather, the action of wanting to occupy more space in society, leads to us reducing the space in which we physically took up. This conflicting messages around how a women's body should be constructed in society led to an increase in engagement with diet culture.

### *Diet culture*

Diet culture is popularly defined as a system of beliefs that: 1) idolizes thinness equating it to health status and moral virtue, 2) promotes weigh loss as a way of gaining higher social status, 3) turns food into an issue of morality, 4) oppresses and criticizes those who do not match up to society's idea of 'health', resulting in harming women, femmes, trans folk, people in larger bodies, people of colour and people with disabilities (Harrison, 2019). Practices of dieting positions the body as an enemy, "an alien being bent on thwarting the disciplinary project" (Bartky, 1997, 66).

The female dieter in the 1960s onwards was "defined by her embodiment of the era's technological, consumer, and gender advancements in her fight against fat" (Gagliardi, 2018. p. 66). This war against fat positioned the dieting woman to be perceived as a 'modern' woman, one who engaged in nutritional sciences whilst engaging in consumerism. Advertisements were designed with the purpose of informing women of their need to shrink, women's magazine stories were full of different diets such as the 350calorie air-hostess diet or the sexy pineapple diet (Wilks-Heeg, 2017). In conjunction with diet suggestions, advertisements made available methods of appetite suppression such as meal replacement shakes, diet pills and Ayds reducing plan candy[2] (Decades Staff, 2016). Personal magazine stories placed women's weight-loss success at the

frontier, with before and after photos along with before and after measurements, used to demonstrate the idea a ‘larger body’ is a temporary body (Gagliardi, 2018).

The dominant messages around fat being the enemy was further embedded into society through the role of medical professional who were placed in a position of power as the governors of health (Foucault, 1977). Obesity is constructed as a social epidemic and reproduces larger bodies as unhealthy and lacking virtue and morality (Grønning et al., 2012). As diet culture gained more prominence, the waist and hips of the ideal women became smaller and smaller (Seid, 1994). The body of a thin woman illuminates particularly where the ideal figure of women changes to meet the satisfaction of the male and medicalised gaze. Though AN was recognised in the medical community, in the general society, AN was largely only known by those who had personal experience with it.

### *AN: In the public eye*

From the 1970s AN was brought to social prominence with medical professionals increasingly publishing articles, outlining the risks and warning signs of AN to parents (Brumberg, 2000; Gordon, 2000). This created both a flurry of worry for those with children, while it also increased the interest from academics and theorist.

More recently, AN has been the subject of feminist theorizing, A medical lens often looks at the body in terms of performativity and function (Goffman, 1961); in contrast the feminist perspective of the body and the space it occupies is more complex. From this standpoint, practices of self-starvation do not relate to thinness, but rather are symbolic of women’s greater struggle within society (Gordon, 2000; Macsween, 1993). Marilyn Lawrence and Susie Orbach are regarded as two of the most prominent feminist theorists whose work focuses primarily on AN. Lawrence (1984) purports that AN is a strategy of

control on two levels. The first level focuses on the female attempting to obtain control over themselves and their bodies, through eating practices and not-eating strategies. The second level is situated in terms of morality where the 'anorexic' women attempts to gain control over their needs and desires. Gaining absolute control and being perceived as perfect is motivated by feelings of being out of control. These feelings of being out of control are then represented through fear and preoccupation of becoming fat. Women tell themselves that they are glutinous and fat (Macsween, 1994). Therefore, rather than understanding AN as a fear of becoming fat, self-starvation is positioned as an attempt to gain control where their life feels out of control (Bruch, 1973).

Whilst Orbach (1993) offers a similar perspective of AN, her focus is on the desire to be thin as an expression of a confusion women feel about the amount of space in which they can occupy. Within Orbach's perspective, she suggests that food denial is a symbolic act and a modern practice woman have engaged to gain self-assertation (Orbach, 1993). Orbach theorises that AN is complex personal response to interpersonal, intrapersonal, societal and political distress. She argues that AN is a restraint on women's desires, emotional needs and femininity (Orbach, 1993). AN is argued to be a manifestation of centuries of self-hate held by women within society, a war in which they turn inwards of themselves as they attempt to grapple with what space and how they can situate themselves in a society that is designed for males.

## Current research on AN

Current research in AN is focused on examining the aetiology of AN with a specific focus on the neurological and genetic underpinnings. As of 2019 the AN Genetics Initiative (ANGI), which is the largest world-wide genome study on AN, identified that there are

eight significant loci on genes. These findings defined AN as being both a psychiatric and metabolic illness (Watson et al., 2019). While this focus illuminate's important information about AN, it undermines the socio-cultural, socio-political and the lived experience of AN and rather reduces it to biomolecular properties. Therefore, in doing so, misses the lived experience. While genetic and neurological research dominates the current research for AN, there is a push back to this within the critical health psychology sphere, where research is qualitative based and focuses on the lived experience of eating disorders and focuses on dismantling the rigid diagnostic criteria to provide a more humanistic understanding and examination of eating related distress and recovery. As biomedical perspectives have dominated our understanding of AN since the 17th century it is hardly surprising that we continue to conceptualise AN through this lens. While attempts to understand it from a critical and lived experience are often met with contention.

## Summary

Within this chapter I have provided an overview of the genealogy of AN and how this genealogy has been shaped by certain practices within society. These practices in society have been shaped and informed by powers in society that govern and legitimize certain practices, resulting in the development of different discursive practice. Starting in the early 14th century, the act of self-starvation has been understood through a religious discourse where Holy-anorexia was seen as impacting young women and it was tied to ideas of purity, morality and perfectionism. While it is outside of the scope of the thesis to create a causal link between Holy-anorexia and modern-day anorexia, this idea of purity, morality and perfectionism is something that is reproduced in how AN is understood in the 1970s and even today. The development of the diagnosis of AN is of importance as it represents a time where those who legitimised knowledge and held power

in society transitioned from a religious to a medical discourse. These power dynamics in society remain today and rather have just changed location of the people in power. The medical profession often is seen as legitimising knowledge through abiding to the scientist-practitioner model Within this transition the body went from being understood from a monism to Cartesian dualism. This transition has a particular impact in how AN was understood as it alludes to the idea that the mind and body are two separate beings, where the body is able to be reduced to biological function and therefore treated as if it was diseased- the result of a mismanaged body. This idea becomes particularly prominent in the development of the DSM. AN is now understood through the pathologizing of a stringent criterion where those who present with such symptomology reflect a protesting body that needs to become docile and the diagnosis works to begin this process. As society changed, the 1960-1970s was of importance in understanding how AN has been legitimised and regulated by the DSM. As discussed, the 1960s saw the emergence of the second wave of feminism and as a consequence the way in which the female body was regulated within society changed from being a body that was often hidden to a body that was modern, exposed and engaged in diet culture to abide to diet culture and normalised standards of femininity. This change of discourse around how the female body is expected to look and perform in society changed the way in which we have understood AN in today's context. As society predominately understands AN through the DSM, AN is understood through a Cartesian dualism perspective where the body has been mismanaged and therefore is pathologized to be a diseased with the 'illness' known as AN. This disease is viewed as resulting from a biopsychosocial paradigm, where the focus is primarily located on the biological, however when the social is considered it is through the idea that AN is a culturally-bound illness, one that is influenced by the 'thin ideal'.

## Defining AN

While this chapter has examined the genealogy of AN, this thesis attempts to disengage and critique the predominant idea that exists of AN. Rather than engaging in the reductionist perspective that the DSM holds, this thesis instead views AN through a feminist discourse. My thesis will adopt Orbach (1986) and Lawrence (1984) perspectives of AN, where the act of self-starvation extends beyond the physical and materialistic weight of the body. Furthering this, the act of self-starvation is not an active engagement of the 'thin ideal'; rather it is a unique expression of complex socio-political issues that are unique to the individual coupled with contemporary sociocultural concerns about gender, power , femininity , subjectivity and embodiment ( Malson and Ussher, 1996).

It is at this point I also want to recognise that while I am framing AN through a feminist lens, my thesis does intersect with the fact the act of self-starvation does involve an ontological reality, where the symptoms of self-starvation are real and therefore at times do need to be intervened upon so that the body survives. While there is a level of ontological reality associated with AN, this does not deny that AN is a socially constructed phenomena, where the way it is understood, interpreted and treated is dependent on the dominant societal discourses and the time, space and culture in which it exists.

# Chapter Two

# Literature Review of inpatient treatment for AN

Treatment for AN focuses primarily on weight restoration and nutritional rehabilitation, while psychological interventions (typically Enhanced Cognitive Behaviour Therapy and Family Based Therapy) are offered once the individual is deemed by professionals to be cognitively component (Kass et al.,2014 ). For the majority, treatment for AN occurs at an outpatient level, with only a small majority receiving inpatient, hospitalisation or residential treatment. The decision to admit into inpatient, hospitalisation or residential treatment is often determined by the individual's BMI, medical status and depending on country of residence, their insurance status.Of those who receive inpatient treatment, residential or hospitalisation for AN, a small proportion will receive a NGT as part of their treatment. NGTs are rarely utilised in an outpatient setting. My research therefore focuses on the use of NGTs experiences at an inpatient, residential or hospital level.

This chapter firstly examines quantitative literature on inpatient treatment for AN, within this review I focus on treatment outcomes (typically this is defined as treatment adherence and weight gain). I then move to qualitative research on lived experience. I share the results from a meta-ethnography I completed that examined the lived experience of inpatient treatment. Following this I provide an examination of the quantitative literature on NGTs followed by an examination of the two existing qualitative journal articles that explore the lived experience of NGTs. I conclude this chapter with a summary of the examined literature.

## Inpatient treatment for AN

Inpatient, residential and hospital treatment is often a highly medicalised setting where treatment regiments are implemented using stringent rules and routine. Routines and rules within the treatment setting include practices such as bedrest, restricted water/liquid intake, limiting movement, monitoring bathroom usage, set mealtimes where you are watched, NGTs and frequent weighing. These practices are often considered as being a form of behaviour modification and are set to decrease eating disorder symptomatology and increase adherence to regular eating (Halmi & Cunningham, 1975)). While these practices are normalised as being part of the treatment setting, they are also be compared as being a modern-day panopticon where the medicalised setting is perceived as being the panopticon and the individual being compared to the likes of a prisoner (Bell, 2006). Foucault (1977) argues that for a body to become docile in society it must be disciplined. As discipline had moved away from the overt acts of torture and had become more subdue, Foucault (1977) stated that to create these docile bodies, they need to be constantly observed this constant observation was a way of disciplining the body without making a mark upon it. Consequently, when the body becomes constantly observed the individual in that body corrects their behaviour. A way Foucault (1977) postulated such observation was through using Jeremy Bentham's 1791 model of a panopticon prison as a metaphor for control and discipline. Therefore, the panopticon represents the greater observation that exists within society to create docile bodies.

Although inpatient, residential or hospital-based treatment is comparable to a modern-day medicalised panopticon, admission into such services is often difficult, laden with certain privileges and offered to those who are considered to be the 'sickest', therefore, this often creates an idea of exclusivity in the treatment setting. Despite how difficult it is to access treatment, when individuals do, a reported 20.2% to 49.6% of patients self-

discharge prematurely from inpatient treatment (Wallier et al., 2009). Due to the serious nature of AN, it is important to understand why there is such a high and varied rate of treatment dropout in the inpatient, residential or hospital setting.

Wallier et al. (2009) conducted a critical literature review which included seven studies. The review focused on factors that led to drop out from inpatient, residential or hospital treatment for AN. Within the review, Wallier et al. (2009) identified that there would likely be differences associated with younger and older patients; this is because younger patients are minors, so they have less control over their treatment and less opportunity to voluntarily leave. Duration of AN is a risk factor for drop out and patients who are older and have a longer duration of AN have a higher rate of discharge in contrast to those who are recently diagnosed. In contrast Wallier et al (2009) found, younger patients were observed as having a lower BMI on admission and the lower the BMI the higher the rate of risk associated with treatment dropout. It was hypothesised that this was to do with the crease in length of hospitalisation, as this too was a predictive factor of patient dropout. However, a further study examined in Wallier et al (2009) presented conflicting information suggesting that the higher the admission BMI, the more likely the individual was to drop out.

Wallier et al (2009) also found a further risk of treatment dropout related to the diagnosis/diagnoses of the individual in treatment; those who were diagnosed with AN binge/purge subtype were more likely to drop out in contrast to those who had a diagnosis of AN restrictive subtype. Additionally, those who scored highly on the "Maturity Fear" subscales on the Eating Disorder Inventory II (EDI-II) or the Eating Disorder Examination (EDE), found that greater fears of maturity[3] as associated with a higher prevalence of dropout. This effect, however, was not as prominent in studies that used Eating Disorder Inventory (EDI) and was only marginally significant.

Finally, the treatment modality was influential in treatment dropout rates (Wallier et al, 2009). When dropout was seen earlier in the treatment experience, this was often associated with impulsivity and immaturity, which was measured through psychometrics. In contrast, treatment dropout later on in treatment often reflected an early discharge from treatment, where the treatment facility discharged due to the individual not meeting the agreed upon weight gain, thus reflecting what seen as a lack of progress. A further influencing factor was that stricter treatment programs were also associated with a higher percentage of dropout.

While the Wallier et al. (2009) review provides information about why an individual might drop out of treatment for AN, the focus of the review is on what would be considered individual responsibility, subsequently placing the blame on the individual for the lack of treatment adherence, rather than exploring factors relating to treatment itself. Focusing on constructs such as age, BMI, duration of illness and correlation between psychometric measure results and treatment drop out excludes the story of why the individual dropped out of treatment. Consequently, the reasons for dropping out have been missed and rather such studies act as a way of further pathologizing the individual, specifically regarding the idea that those with AN are often treatment resistant. Along with this it neglects to examine any structural or societal issues associated with the treatment setting.

Though the quantitative literature that examines inpatient treatment and the associated dropout rate illuminates that there is a high rate of drop out associated with the current treatment modalities and that there are some specific characteristics associated with those who are more likely to drop out, there is a large gap in our understanding; largely, one focused on the lived experience of inpatient treatment. Developing an understanding of

what it is like to experience inpatient treatment is an important part of understanding why treatment outcomes are often poor and dropout rates are high for those with AN.

## Lived experience meta-ethnography

As there is a paucity of literature examining the lived experience of inpatient treatment for AN, I conducted a meta-ethnography to examine what are the key ideas and themes in the lived experience of inpatient treatment (see Appendix D for a more detailed explanation of this study).

The meta-ethnography consisted of 10 journal articles and aimed to explore how inpatient treatment was experienced. (Appendix E). was a total of 10 themes overall but four themes relative to this current thesis and literature review I will discuss focus on weight and food, lack of access to psychological support, inpatient treatment as traumatic and lastly, not being 'just another anorexic.

### *Focus on Food and Weight*

The most prominent reoccurring theme across the review was the idea that treatment was overly focused on weight and food. The focus on weight and food was experienced two-fold. Firstly, de la Rie, et al (2006) as well as Rance et al (2017) reported that participants reflected on weight often being a barrier to accessing inpatient treatment, with them frequently reporting that access to treatment was often dependent on having a low body weight. Furthering this, participants in Rance et al (2017) indicated that the need to have a low body weight to access treatment was often interpreted as a motivation to lose more weight and contributed to the belief that they were not sick enough. When comparing this idea to Wailler et al.'s (2009) critical review, where lower BMI is perceived as a factor that contributes to drop out, and the current meta-ethnography review indicating that a higher BMI (that is still underweight) is associated with denial into treatment, this suggests there are other structural issues at play around access and the actual treatment

experience. In addition to this, the system is contributing to individuals with AN losing more weight in attempt to have their illness validated and receive treatment.

Further to the focus on weight acting as a barrier to inpatient treatment, once the individual was accepted into a treatment program, they experienced treatment through a biomedical discourse based on weight restoration. Therefore, participants commonly were drawing on dominant biomedical discourses reflecting the discourse and talk of the practitioners caring for them. This reflects a similar notion to how women in the 1970's started to engage more heavily in diet culture so they could uptake the position of a 'good women' in society.

In Bannatyne and Stapleton (2017), Colton and Pistrang (2004), Rance et al (2017) and Wu and Harrison (2019) participants mentioned how treatment focused on principles of behaviour modification in attempt to regulate normalised eating patterns and weight restoration, while psychological needs were neglected. While participants recognised that they were underweight and acknowledged the need to gain weight, they believed that the way in which treatment set out to normalise eating while being solely focused on weight contributed to more distress and resistant behaviours and ignored their emotions (Offord et al., 2006).

In addition, the treatment of eating was seen as very abnormal, such as being made to drink the salad dressing, weigh-out food, having to lick plates clean, stringently being watched while eating or having strange combinations of food that would not be reflective of an outside meal all contributed to further engrained abnormal behaviours around food (Long et al., 2011; Rance et al., 2017). Thus, the focus on food and weight according to inpatients reflects the systemic power relations that exist within a residential setting rather than a desire to understand individual patient's needs.

*A want for psychological treatment*

The second theme under examination was the participant's want for psychological treatment. Within an inpatient setting the focus is often on medical stabilisation and weight gain. The individual is often assumed to be experiencing cognitive impairments and therefore unable to effectively engage in therapeutic treatment (Bannatyne & Stapleton, 2018; Colton & Pistrang, 2004; Wu & Harrison, 2019).

Participants expressed that the biomedical view of cognitive impairment neglected the feelings and distress experienced. Instead, participants were often told that once they reached a healthy weight this distress would no longer be present. However, participants still experienced a degree of distress and emotional deregulation at a healthy BMI (Bannatyne & Stapleton, 2018; Colton & Pistrang, 2004; Wu & Harrison, 2019). Therefore, participants expressed feeling as if their emotional and psychological needs were not important and contributed to the belief that staff wanted to "fatten them up" but not actually help them (Offord et al., p. 381). Furthering this, patients felt that when they were in inpatient treatment, therapeutic support would have been beneficial as it would have supported the distress associated with weight gain and helped them adjust to changes in routines and bodily functions, (Rance et al., 2017).

Finally, in the Offord et al. (2006) study, participants reported that the lack of psychological treatment led participants to believe that health professionals did not understand that there was an underlying cause of AN that existed outside of weight and food. Ultimately this led to feelings of frustration, being upset, confused, and feeling misunderstood. Participants from Sheridan and McArdle (2006) suggested these feelings are contributing to under engagement and resistance in treatment.

This theme therefore indicates that when individuals enter treatment, their idea of what treatment entails is mismatched with the reality of treatment. This leads to feelings of

frustration and as if they are unsupported in recovery. Consequently, participants allocate this as being a reason for the lack of treatment engagement.

### *Treatment as traumatic*

The third theme relating to inpatient treatment reflected the idea that inpatient treatment was experienced as traumatic for some participants. Bannatyne and Stapleton (2018) found that within their research 91.4% of their sample size reported experiencing inpatient treatment as traumatic. The consequences of this trauma were flashbacks, nightmares and dissociation with some persisting past treatment discharge (Bannatyne & Stapleton, 2018; Wu & Harrison, 2019). Subsequently, the effect of treatment trauma often surpassed and felt worse than the underlying cause of their eating disorder, this often-left individuals feeling voiceless and disempowered within their life. Trauma related to eating disorder treatment seemingly could be broken down into two main categories; firstly, the use of interventions such as restraints and NGTs and secondly, measures used to control their behaviour.

Fox and Diab (2015) found that the use of restraints on an eating disorder ward is often considered traumatic for the individual receiving restraints, others on the ward witnessing restraint use, as well as staff administering the treatment. Fox and Diab (2015) expanded on their experience, citing that the use of restraints often led participants to feeling as if the AN was their only safety net due to the sense of control associated with resisting such treatment. This resulted in the participants finding it difficult to engage in recovery as they perceived the AN as a protective mechanism. This belief created a dichotomy where the use of restraints led the individual to rely on their eating disorder as a protective mechanism, then at the same time, the further they engaged with their eating disorder, the more frequent restraint events, resulting in a vicious cycle.

The use of NG tube as punishment for not following treatment regimens is also a form of restraint and can be traumatic for some individuals (Bannatyne & Stapleton, 2015; Fox & Diab, 2015; Zugai et al., 2012). Fox and Diab (2015) found the use of the NGT was experienced differently between individuals; while some individuals reported it was a relief as it meant that it took the responsibility away from them, others report that the experience was traumatic and often led to an increase in symptoms from comorbid disorders such as post-traumatic stress disorder, depression, anxiety and obsessive compulsive disorder. While Bannatyne and Stapleton (2015) study notes that nasogastric feeding was perceived as traumatic, they do not elaborate on why this was. A further study by Zugai et al (2012) mentions that NGTs were viewed unfavourably particularly in the context of being used as a punishment for breaking rules on the ward. This was attributed to the discomfort associated with insertion; however, the study does not expand beyond this. Therefore, while it is viewed as traumatic, current literature does not examine these statements any further and illustrate the need for further research in this area.

The other aspects of treatment that were consider traumatic revolved around the methods used to control supposed resistant behaviour. Zugai et al (2012) found that bed rest was construed as traumatic. Bed rest is commonly used at the start of treatment in attempt to limit the energy exerted. When it was used as a punishment to isolate individuals from others on the ward this often resulted in participants struggling and restraints being used as a way to ensure bed rest was carried out (Zugai et al., 2012). Bannatyne and Stapleton (2015) study suggested a similar idea where the use of isolation as a punishment was often considered traumatic. Participants in this study reflected that isolation led them to engage further in thoughts of being worthless, where participants in Offord et al (2006)

indicated participants punished with isolation experienced thoughts of not being deserving of life.

A further example was illustrated in the Zugai et al (2012) study around time limits set for eating meals. It is common during mealtimes for those on eating disorder wards to be given a time in which they have to complete a meal and if they do not, they either receive a bolus of nasogastric feed or a supplement drink to complete. Zugai and colleagues found nurses forcing them to drink the supplement even when they ate within the allotted time, resulting in further distress for the individual (Zugai et al., 2012).

Other punishments reported by inpatients were not being able to see families for two-weeks, having rules around what can be talked about, everything being timed, and other stringent rules and regime (Colton & Pistrang, 2004; Eli, 2014; Offord et al., 2006) This suggests that the effects of treatment trauma often surpassed and felt worse than the underlying cause of the individual's eating disorder which often left individuals feeling voiceless and disempowered within their life. Ultimately, all participants in all the qualitative studies discussed here found the treatment experiences felt oppressive, regimented and traumatic.

*Just another anorexic*

The final theme that emerged from the lived experience perspective was the idea of not being 'just another anorexic'. Participants reported that their emotions, thoughts, feelings and behaviours were tied to them being an 'anorexic', rather than an individual (Bannatyne & Stapleton, 2018; Colton & Pistrang, 2004; Eli, 2014; Fox & Diab, 2015; Offord et al., 2006; Rance et al., 2017). Participants reported a debate within themselves. At one end of the scale individuals reported wanting to be viewed as more than their symptoms. While the other end of the scale, the individual was viewing themselves as 'just anorexic'. These two arguments are often placed in juxtaposition to each other and

it is not uncommon for individuals in treatment to oscillate between the two. Firstly, when individuals in treatment experienced staff treating them as if they were just anorexic, rather than an individual, this led to feelings of being misunderstood, frustrated and feelings of disempowerment (Bannatyne & Stapleton, 2015). Furthering this, patients often felt that staff placed those with anorexia as a collective, creating what patients described as a simplistic and superficial understanding of AN, where the individual was lost within the treatment and instead patients became a collective eating disorder (Bannatyne & Stapleton, 2015; Eli, 2014; Offord et al., 2006). As a result, patients felt as if they were not being seen as themselves and rather a walking diagnosis, indistinguishable from one another.

On the other end of the spectrum, participants found that admission onto an eating disorder ward legitimised their eating disorder, however it further embedded the idea that they were anorexic, rather than a person with a diagnosis of AN. Consequently, they viewed themselves as indistinguishable from their anorexia and therefore struggled with the idea of recovery (Bannatyne & Stapleton, 2015; Eli, 2014). Bannatyne and Stapleton (2015) discuss these views as being tied to the person's identity and outlined how important it is for treatment to consider what it means for their identity if they are not just an anorexic. Though treatment legitimised their diagnosis of AN, it presented individuals with the issue of wanting to be treated as an individual while simultaneously leading to believe that all they were was anorexia. This creates a difficult dialect for individuals to navigate within the treatment setting.

In summary, when research focuses on the lived experiences of inpatient treatment, residential and hospitalisation, participants experience an array of barriers in the treatment setting. Participants experienced frustration over the focus on weight gain and saw the withholding of psychological treatment before weight maintenance or restoration as

punitive. Interventions such as restraints, bedrest and NGTs were viewed as traumatic. Behaviour modification focusing on the normalisation of eating (i.e. licking plates) was often viewed as abnormal to those in treatment which further demonstrated that staff had a lack of knowledge around what it means to have AN. Finally, the idea of being 'just an anorexic' is something that participants felt was portrayed by staff, but at the same time the treatment setting also caused them to embody this idea of 'being anorexic'. These results offer a striking contrast to the quantitative literature reviewed, which focused on personal characteristics around why treatment might not be successful and why there is such a high dropout rate. Therefore, there seems to be an incongruence between the professional perspective of treatment outcomes and the lived experience of treatment and how the two interrelate. Further research examining specific aspects of treatment is needed to understand to what degree inpatient, residential or hospitalised based interventions are impacting or influencing the treatment experience.

## NGTs and AN

The use of NGTs in the treatment for AN has been of interest to largely those who work in the field of dietetics. Subsequently, the majority of studies looking at nasogastric feeding examines the efficacy around their use and also the rate at which you can safely refeed someone. This section of the critical literature review will start by examining what the quantitative literature says about the use of NGTs when used as part of the treatment for AN. Following this, I will examine the two existing pieces of qualitative work that examine the meaning attached to NGTs when used in the treatment for AN.

Dietetic research examining the use of nasogastric feedings relay that the primary goal of treatment is to reverse malnutrition and health complications associated with malnutrition

(Garber et al., 2015; Kells & Kelly-Weeder, 2016; Hart, et al., 2013; Rocks et al., 2013;). Garber et al. (2015) discuss how the refeeding process is influential to long-term recovery and that faster weight gain and higher weight upon discharge is predictive of weight recovery at one-year post treatment. Similarly, Kells and Kelly-Weeder (2016) report that weight is used as an indicator of treatment progress and this progress has a direct implication on recovery and long-term outcomes. While both of these ideas are hopeful, they do present a more simplistic perspective of AN where the body is constructed from a Cartesian dualism perspective and recovery is viewed as synonymous with weight gain. Thus, rejecting the possibility that AN can exist outside of a biomedical profile.

In accessing the use of NGTs, Kells and Kelly-Weeder (2016) conducted an integrative review. The review aimed to explore outcomes of nasogastric feeding in a population with AN with a specific focus on making recommendations for future research, policy and practice. 19 studies were included in the review.

As stated in the Kells and Kelly-Weeder (2016) review, there is currently no clinical guideline for when nasogastric feeding should be utilised when treating AN. Furthering this, they postulate that due to the underlying pathology associated with AN, the NGT might be manipulated, removed or there will be non-adherence to the intervention as it is expected that those with AN have difficulty engaging in treatment protocols that encourage weight gain. Therefore, in Kells and Kelly-Weeder review, they examined physiologic outcomes, gastrointestinal symptomology, nasogastric treatment adherence and psychiatric outcomes.

The review found that in terms of physiologic outcomes, the average length of stay when receiving nasogastric feeding was 79.5 days with a range of 1-599 days and that weight gain ranged from 5.7kg to 15.9kg. In addition to this, the review compared nasogastric

feeding to oral intake and found that those who received nasogastric feeding gained more weight than those who received oral intakes. Adding to this, when nasogastric feeding was used in conjunction with cognitive behavioural therapy, this saw a significantly higher rate of weight gain at the 8-week mark than those who had received nasogastric feeding by itself or cognitive behavioural therapy by itself. While these results were initially positive, there was no difference in long-term weigh gain with both the oral intake group and nasogastric fed group, demonstrating no differences in overall weight gain at the conclusion of inpatient hospitalisation. A further study in Kelly and Kelly-Wedder (2016) review indicated similar results, where patients were given a NGT if they failed to meet the weight target of one kg of weight gain per week. While those then given a NGT gained more weight during their hospitalisation, this weight gain however was not predictive of long term maintenance or weight gain and there was no significant difference between nasogastric fed patients and oral intake patients at the six month follow up post discharge.

While the Kells and Kelly-Wedder (2016) review indicates that nasogastric feeding increases weight gain in those with AN, but also indicates the idea that higher and faster weight gain are not indicative of long-term recovery. Furthering this, it allows for critique that the heavy focus on weight gain is not necessary useful in providing a foundation for recovery and rather invites in the idea that psychological input is important in early stages of recovery, rather than withholding until they are at a higher weight.

With the refeeding process there is a level of gastrointestinal distress felt by those in treatment. The Kelly and Kelly-Wedder (2016) review explores how the NGT interact with this distress. Six out of the 19 studies mentioned distress and NGTs, however the symptoms were inconsistent amongst the studies. One study in the review reported that there was a nonsignificant increase of nausea and abdominal pain associated with

nasogastric feeding, while a different study described non-significant rates of increased abdominal bloating. A third of individuals reported that cramping and bloating persisted in 30% of those who received nasogastric feeding. In contrast two studies reported either no difference or improvement to gastrointestinal distress when fed via a NGT. Therefore, results were mixed on how nasogastric feeding interacts with gastrointestinal symptoms. What this review does indicate is the complexity and importance of listening to those receiving nasogastric feeding. It is key to recognise that gastrointestinal distress can be a side-effect and that this is not necessary a reflection of trying to mitigate weight gain or in the individual's head.

In terms of adherence to treatment, four of the studies reviewed reported on if those receiving nasogastric feeding had manipulated or removed the NGT in some way (Kelly & Kelly-Wedder, 2016). It was found that two to five participants per study removed their NGT against medical advice, while two to three participants per study manipulated the NGT or feeding pump. While lack of treatment adherence is attributed to eating disorder pathology, specifically the DSM criteria around mitigating attempts to gain weight, there has been no research on nasogastric feeding examining what removing or manipulating their nasogastric feeding tube means to the individuals and why they did it. Rather, this lack of treatment adherence is pathologized and then the individual is viewed through a child-like discourse, where they are perceived as 'naughty' and treatment resistant.

Finally, the review examined psychiatric outcomes (Kelly & Kelly-Wedder, 2016). As the studies under review are quantitative, psychiatric outcomes are assumed through a change in psychometrics and these psychometrics typically take the form of measures such as the Eating Disorder Inventory (EDI). The use of such measures is problematic as the psychiatric outcomes are based on symptom reduction in the form of weight gain or a reduction in specific behaviours relating to eating disorders (Berg et al, 2012) and do

not necessarily account for how the individual is feeling or capture the distress related to the underlying cause of the eating disorder. Furthering this, when in an inpatient setting, the individual has been heavily restricted in the behaviours they are able to engage in (such as bedrest, enforced eating and locked bathrooms preventing purging), these behaviours are not necessarily reduced and rather it is an artificial picture of a complex situation. Kells and Kelly-Weeder (2016) review found that six of the 18 studies focused on physiological outcomes, with the six studies producing a wide variety of improvements in psychiatric symptomatology following nasogastric feeding. All six studies indicated that while there was a decrease in eating disorder behaviours such as purging, there was no overall significant difference in eating disorder symptomology after receiving nasogastric feeding, and the same can also be said about oral intake only.

One of the main arguments for using nasogastric feeding, as stated at the start of the review, is the belief held by professionals that this approach leads to faster and higher levels of weight which in turn is influential in producing long term recovery. However, as indicated in this review, there was no significant reduction in eating disorder symptomatology and the higher rate of weight gain seen in those who receive NGTs is often not maintained long term. This brings into question, outside of when medically needed, what is the role of nasogastric feeding in the treatment for AN. Repeating Kells and Kelly-Wedder (2016) idea, there is need for further research in the area of nasogastric feeding, specifically to focus on the development of a clear set of guidelines for when nasogastric feeding should be utilised.

In comparison to the quantitative literature, the two qualitive studies focused on the lived experience of NGTs. The first qualitative study conducted by Neiderman et al. (2001) used semi-structured self-report questionnaires to explore the subjective retrospective experiences of nasogastric feeding for AN. The questionnaires were sent to parents and

patients from two adolescent eating disorder wards in the United Kingdom. Neiderman et al. (2001) received 58 responses in total, with 37 of responses coming from parents of children and 21 responses from those who had personally experienced nasogastric feeding. The results were then analysed using thematic analysis.

Though Neiderman et al. (2001) was able to accumulate a large sample for qualitative research through using survey research, the response of participants was greatly restricted as answers to the question were dependant on the questions asked in the survey. Furthering this, survey research also risks eliciting response bias (Mazor et al, 2002). This can have an impact on the results of the study.

Neiderman et al. (2001) study produced five themes; consent to nasogastric feeding, resistance to nasogastric feeding, reactions to nasogastric feeding, alternative to nasogastric feeding and advice to others. Each of the sections integrates the parents' responses as well as the response of the individual who experienced it. When examining themes relating to consent, 71 percent reported that they had not consented to the procedure reasoning they had feared weight gain and a loss of control over their intake (Neiderman et al., 2001). 29 percent reported they had consented to the procedure. This consent was given for a number of reasons, including that they had wanted the control to be taken away from them, a fear of being placed under the mental health act, a desire to get better and so they could be discharged to then go home and lose the weight again. Of the parents, the large majority had given consent for their child to receive nasogastric feeding. In terms of resisting nasogastric feeding, 63 percent of those in the study reported physically resisting the passage of the NGT and feedings (Neiderman et al., 2001). Those who resisted were then restrained by staff or family, with a further 55 percent then reporting removing their NGT. A majority of those who had removed their tube had removed it five times or more. However, one reportedly removed it over 1000 times, and

another sabotaged the feed. The theme of resistance is concluded by interpreting the act of resistance as a way of negating any attempts for nourishment. The interpretation provided, while logical, relies on a biomedical discourse to understand the behaviour and frames it as an act of defiance that reflects a diagnostic criteria, rather than exploring the meaning behind the behaviour and how the individual made sense of their behaviour. In providing this critique, it is important to contextualise that this study was the first study to explore the lived experience of nasogastric feeding.

When examining the theme 'reactions to nasogastric feeding', 66 percent of participants reflected that they regretted it at the time, but in retrospect it was helpful (Neiderman et al., 2001). While the second group which was 44 percent of participants reflected that they hated it then and hated it now. For those who hated it then and hate it now, there reflections centred on the NGT being intrusive, how it went against their wishes and that it had been an unhelpful intervention.

Though the study explored alternative to nasogastric feeding, the overwhelming response was that there was no alternative, however it should only be done in a caring manner and not in anger.

Finally, the theme 'advice to others' centred around participants providing advice to those who find themselves in a similar situation (Neiderman et al., 2001). Participants advice ranged from trying your hardest to eat as it is a horrid memory to have, food not being the issue and it is only a symptom of something deeper, so to focus on that instead, or offering advice on eating is preferable as nasogastric feeding has more calories than oral intake. Several participants also reflected on the positive experience, stating that it had been a necessary tool in helping with recovery.

Neiderman et al.'s (2001) study is the first to examine the lived experience of NGT. The results and discussion section are written in such a way that there is limited interpretation to the thematic analysis and rather it relies on the percentages from the participants response to tell the story, with occasional quotes being used to demonstrate the theme. Where interpretation is provided, it relies on the use of biomedical discourse and views behaviour from a pathologizing perspective, rather than exploring the individual's subjective experience and what the behaviour meant for them. However, as this study was the first to explore the lived experience of NGTs, it provides a starting point for further and more in-depth research to be conducted, specifically, face-to-face interview-based research.

Following Neiderman et al. (2001) study, Halse et al. (2005) conducted a study on the lived experience of NGTs. This time the study utilised in-depth semi-structured interviews, interviewing 23 adolescent females who were currently residing in a specialist eating disorder ward in Sydney, Australia. Participants were encouraged to discuss the issue that had the most relevance to them. This resulted in 17 of the 23 participants discussing their experience with nasogastric feeding. The study, therefore, did not start out with an initial research question relating to nasogastric feeding, rather it unfolded naturally amongst interviews with participants. This natural emergence indicates that nasogastric feeding is a pivotal part of treatment that has an impact on how treatment is embodied and experienced.

Halse et al. (2005) thematically analysed the data relating to nasogastric feeding utilising a constant comparative analysis that was informed by social constructionist theory. In doing so Halse et al. (2005) identified four major categories relating to nasogastric feeding; unpleasant physical experience, a necessary or helpful intervention, a physical

psychological signifier of anorexia, a focus in a struggle for control and the multiple meanings attached to NGTs.

The first category examined the idea of the NGT being an unpleasant physical experience highlighting that both the insertion of the NGT and having a NGT produced a degree of discomfort which persists for some time. This idea appeared more frequently when the insertion procedure was not explained or when staff had not been trained adequately in the procedure. Halse et al. (2005) interpreted this discomfort as reflecting the intrusive nature of the procedure. However, they do not expand beyond this statement.

The second category looked at the NGT as a helpful or necessary intervention (Halse et al., 2001). This category posited itself around the idea that although it was an unpleasant physical experience, it a was necessary and often helpful medical intervention. This idea was specifically focused on the normalisation of the NGT as it was a standard part of the program they were in, it allowed participants to see the NGT as an aid to recovery. The tube was conceptualised as aiding in recovery from a biomedical discourse, where participants framed their experience as being beneficial as they explained the mechanical nature of how nasogastric feeding works. Participants also framed the experience as tricking the anorexia, as the NGT disguises the food.

The third category positions the NGT as a signifier of AN. Some of them found the NGT was experienced as a confrontation of the reality of having AN and made them accept their diagnosis. Along with the personal signifier it became a public signifier where it marked them as being ‘anorexic’. Halse et al. (2005) interpreted this category as a complex entanglement of the personal and public recognition of illness.

The fourth category focused on the broader struggle for control. This category centres around how nasogastric feeding creates a struggle for control over the management of

one's weight, behaviour and sense of self. Halse et al. (2005) expands on this idea by providing an interpretation that participants who attached this perspective onto the NGT were more likely to perceive the NGT as a form of control and punishment for non-compliance. These participants were more likely to resist the NGT and engage in a number of covert behaviours in attempt to regain this broader sense of control.

The final category focused on the multiple meanings attached to nasogastric feeding. This category illustrated the often contradictory and multiple meanings participants attached to NGTs. Halse et al. (2005) postulates that these multiple meanings are a rejection of the idea that those with AN suffer from cognitive distortions which lead to informed judgement, which in turn results in the resistance of particular forms of treatment and rather situates this theme in Burr's (1995) theory of social construction supporting the idea of personhood and subjectivity.

The work of Neiderman et al. (2001) and Halse et al. (2005) provide a framework for future research to be conducted on the lived experience of NGTs. Both studies focus on an area of eating disorder research that is grossly understudied and highlight that there is a level of complexity to the NGT felt by those who have experienced it as part of their treatment. However, due to limitations with the methodology, the methodology was not necessarily catered towards exploring this topic in-depth rather it was something that came out at during the analysis stage. Following this, while both Neiderman et al. (2001) and Halse et al. (2005) had a larger sample size for qualitative research, the sample was homogenous, with participants having received their NGT during a similar time frame, age, country and treatment facility. Therefore within the sample there was little variance. Though this is not necessarily a bad thing, having a study with a more heterogenous sample in a homogenous experience could allow for a deeper understanding of the lived experience.

Finally, in terms of results, both studies had several similar themes, specifically around NGTs signifying a greater battle for control, a confirmation of their diagnosis and acknowledgement of the trauma aspect (Halse et al., 2001; Neiderman et al., 2001). The discussion for what these results mean is limited and did not fully explore or provide a discussion outside of what the participants said. Therefore, it is lacking the researcher interpretation and theory. This could possibly due to the time in which the research was conducted (early 2000's) was a lot more conservative in accepting critical qualitative research..

## Summary

Quantitative literature has demonstrated that there is a high rate of premature discharge rate for those in inpatient treatment for AN. Wallier et al. (2009) review highlights correlational relationships between individual characteristics and premature treatment discharge; these usually relate to lower admission body weight, higher admission body weight, lower scores on maturity sub-scales in the EDE and EDI-II psychometrics and a diagnosis of AN binge/purge subtype. While the qualitative research examined the personal experience, the personal experience instead highlighted that certain treatment practices such as having to drink the salad dressing, restraints, use of NGT and being treated as if they were 'just an anorexic' lead to treatment disengagement or difficulty with the treatment experience. This indicates that there are incongruencies between professional and lived experience. Thus, to better understand how the lived experience might interact with self-discharge from treatment, it is important to further research specific practices in inpatient treatment to understand how social and policy structures may impact on treatment outcomes.

Kells and Kelly-Weeder (2016) review of nasogastric feeding illustrated that while there is an initial higher rate of weight gain this does even out over the course of treatment and matches those who have treatment as usual (in this case oral feeding with supplements). Then at a six-month post discharge follow up those who had received a NGT as part of their treatment showed similar results to those who received treatment as usual. Therefore, in terms of efficacy apart from an initial increase in weight gain, after the first two weeks of receiving nasogastric feeding there is no difference in treatment outcomes or end results. While quantitative research identified that there is the potential for poor psychological outcomes in relation to nasogastric feeding, the use of psychometrics is limited in exploring this in depth.

In contrast Neiderman et al. (2001) and Halse et al. (2005) qualitative research does provide an examination of the lived experience of nasogastric feeding, both studies are older, have a homogenous population that focuses more so on early adolescent , therefore there are gaps within this existing research.

To further strengthen our understanding of how nasogastric feeding is experienced, having an in-depth study that is specifically concerned with the process of nasogastric insertion and feeding would provide new information to the field of eating disorder research. Adding to this, aiming for a heterogenic sample would allow for a greater understanding of if different treatment centre polices influence the experience.

# Chapter Three

# Methodology

This methodology chapter provides an overview of how I conducted my research. The overall aim of my research was to explore the lived experience of NGTs when used as part of treatment for AN. My research is centred on two questions; What are the participants' experience with NGTs and how did the nasogastric change their relationship with AN.

This chapter starts by examining the epistemology and theory that have guided my study. Following this I provide an overview to narrative research and why this is the chosen methodology for my thesis. I then outline my steps of recruitment and introduce the study's participants. After I discuss the procedure for the narrative interviews that were conducted and the analysis process. After that I outline ethical considerations. Finally, I finish with a discussion on reflexivity and how I positioned myself within my thesis.

## Epistemology and Theory

Social constructionism is the guiding epistemology for my thesis. My thesis is informed by the work of Arthur Frank and Erving Goffman and how they conceptualise the socially constructed body and Michel Foucault work on power, knowledge and the docile body. The work of these theorists is relevant to understanding the power relations that exist within the treatment setting and how these power relations are embodied and experienced for an individual within the medical practice.

## Social Constructionism

Throughout this thesis the assumptions I make regarding how knowledge is constructed is through a social constructionist epistemology. Social constructionism maintains that there is no objective truth for us to discover and rather what is constituted as truth is the result of our engagement with the world (Crotty, 1998). Where society's idea of knowledge is often governed through a positivist lens, which is often reinforced through specific means of power in society (i.e. we understand the body through a biomedical lens and this is governed through the power given to medical professionals), a social constructionism understanding of knowledge asks us to challenge the knowledge that seems inherently given to us; it asks us to take a critical stance of the way we understand the world and ourselves (Burr, 2015). From a social constructionist perspective, our understanding of the world is historically and culturally specific (Gergen, 1973). These historical and cultural understanding of knowledge are consequently influenced by the power relations within society (Burr, 2015). Consequently, what constitutes as knowledge is therefore governed and legitimized by those within positions of power and is sustained through social patterns. The legitimizing of knowledge therefore has implications for those who do not abide by what society has constructed as normal, those that do not align with this idea of normal therefore becomes an issue of morality and abnormality (Burr, 2015).

Social constructionism maintains that to critically examine what we constitute as knowledge; it is necessary to see language as action orientated. With language being action orientated, it requires you to deconstruct what is being said beyond what is normally constituted as a descriptive, reflective or neutral manner (Tuffin, 2005). It is through the deconstruction of language that we are able to gain an understanding of the connection between linguistic structures and the individual's concept of self (Crossley,

2010). Consequently, when we examine individuals' stories beyond the physical words that they are saying, we can provide an interpretation of the world in which they live. It allows us to see into how they construct knowledge and how they situate themselves within the world. Subsequently, whilst a social constructions perspective does not seek to find one defined truth, we are instead able to examine the truths of each individual and how they experience the same phenomena (Burr, 2015).

## The socially constructed body

As a society since the 18th century we have predominately constructed the body through a naturalistic perspective. A naturalistic body is pre-social and biological contributing to one's social identity, the body's ability is legitimized and governed through power relations that exist within society; bodies that can contribute to socio-economic relations and are favoured through legislation are viewed as the normative and natural bodies of society (white, cisgender, able-bodied neurotypical male). Bodies that do not align with such characteristics are viewed as lesser and often are subjected to pathologizing and subordination in attempt to configure the body to align with naturalistic views (Shilling, 2012). Though the naturalistic body is commonly accepted in society, numerous theorists have examined and argue that the body is socially constructed. Whilst terming the body as socially constructed encompasses a range of differing ideas dependent on the theorist, it can be understood as a umbrella term reflecting the opposite of the naturalistic body, suggesting that the body is shaped, constrained, reflective and invented by society (Shilling, 2012). Three theorist whose work situates the body as being socially constructed are Arthur Frank and Erving Goffman, I will discuss their work in further detail and conclude by situating how their work applies to my thesis.

*Arthur Frank*

Medical sociologist Arthur W. Frank positions his work within a social constructionist epistemology. Frank's research positions the body and its development as significant, interacting inextricably with social forces and social relationships (Shilling, 2012). Frank's work examines the impact sickness has on the embodiment of one's body, examining how those who occupy a sic[k] body interact, understand and try to control their body in a society where sickness represents a mismanaged body- as discussed in Goffman's theory (explored further down). The body is viewed both as being socially constructed and embodied, though, there is difficulty associated with communicating the embodied experience of sickness as the body is inarticulate and rather eludes to a language of its own which can only be conveyed through pains and symptoms (Frank, 1995). Consequently, these pains and symptoms translate to sickness, thus whilst the individual inhabiting their body struggles to articulate their experience, postmodernist medicine provides a language and framework for which their story initially is understood through. Physicians assert their authority by imposing a specific language onto the individual's experience, subsequently, the individual mimics such language and their story of illness becomes medicalized, engaging in reductionist perspectives where the body is reduced to biology and physiology and the narrative of embodiment is lost (Frank, 1995; Shilling, 2012). However, when an individual recognizes that their illness has more involved in it then the medical story can tell, they are left trying to make sense of their experience. This new reality is constituted by Frank as being a postmodern divide where the individual's narrative of sickness is no longer positioned as secondary to a medical narrative. Rather, the individual is disembodied, and their narrative is now primary; the

individual tries to make sense of their illness, how the body experienced it and pave a new path for which they understand themselves post-illness (Frank, 1995).

### *Erving Goffman*

Goffman recognizes that while the body is integral to human agency, the embodied experience of living in a body is not autonomous and rather our body is managed through a process of shared vocabularies of body idiom which acts as a way of constraining and managing the body (Shilling, 2012). Goffman developed an analysis that is composed of three parts. Part one and two of the analysis reflect a duality of human bodies where the body is both owned by the individual who inhabits it, however, it is only made significant through society.

Part one of the analysis highlights provides a contrast to the naturalistic perspective held in society where action and identity are biologically controlled. Goffman postulates individuals have human agency giving them control over their self and this control allows for individuals to determine their actions and appearances. The second part of the analysis suggests that the body is not produced by social forces and instead it is the engagement in societal body idiom, which produces rules around how one should manage themselves to be accepted within society. These body idioms consist of non-verbal communication that allude to societal customs and practices. Such idiom reflect how one is expected to act in society in order to be accepted in society. The third part of Goffman's analysis illustrates the relationship between self-identity (virtual identity) and social identity (actual identity). Goffman's analysis suggests that individuals are taught to manage their bodies in order to be significant within society, those who manage their bodies 'well' are perceived as a competent and worthwhile human being, while those who are perceived as

not being able to manage their bodies are viewed as failing and unfit for society. Those who are unable to manage their bodies often belong to stigmatized groups and viewed as not having control over their human agency (i.e. those with mental illness) (Turner, 1991). Consequently, the idea of a well-managed self is determined by body idiom which are not innately built into us and rather are determined by the practices and behaviours within society. Our body is only significant due to these classifications of well managed or mismanaged bodies in society.

### *Michel Foucault*

Michel Foucault is considered pivotal in informing the philosophy underpinning the understanding of the socially constructed body as well as the embodied body (Mcbridek & Kwee, 2019; Shilling, 2012). Foucault's work was concerned with discourse; he postulated that the body is assumed and produced by discourse (Shilling, 2012). Within this epistemological stance, bodies are produced by society, discourse is understood as illustrating the link between daily practices bodies engage in and the power relations that control these daily practices (Shilling, 2012). Thus, within this perspective the body does not exist within the natural setting nor by biology but rather is a political sphere constrained by legislation and knowledge. In understanding the way in which today's body exists and is governed by biopower, Foucault emphasized that to understand the body, there needs to be an understanding or genealogical analysis of the history of the body (Knauz, 2015). While it is outside of the scope of this thesis to provide an in-depth genealogical analysis of the body, Foucault highlights that the body as we understand it is informed by its history and this history is subsequently formed by body idiom (Shilling, 2012). In his work *Discipline and Punish* Foucault illustrates that the body is directly involved in a political sphere governed by power relations. Those placed in positions of

power such as warders, chaplains and medical professionals are given the right to deem behaviour abnormal. The power within these professions created a division of who could hold the power in society and thus, allowed for the pathologizing of behaviour (Shilling, 2012). Consequently, prisons and asylums functioned as a panopticon, where the body whilst not physically infringed upon instead was trained through rationing food, sexual deprivation, corporal punishment and solitary confinement. Punishments within this setting function through security measures; prohibition of entering certain areas, probation, obligatory medical treatment. Such security behaviours are intended to provide further supervision of an individual's behaviour in attempt to create long-lasting behavioural change. Within this perspective, the body acts not as an individual being but rather a production of power-relations, where the body is only useful if it aligns with society's idea of normal. This idea of normality is associated with the consumerist nature of society where the body is seen as being economically useful if it is docile (Foucault, 1977).

Government control has since moved away from the use of prisons and asylums for controlling individuals' behaviours and moved to focus on large scale systems of power. Power relations are now concerned with women's fertility, health, illness and weight. Consumerism culture has since acted as a 20$^{th}$ century panopticon where self-help guides, the diet industry, exercise regimes and so forth function as a means to control the body and present an idea of morality and perfection (Shilling, 2012).

From Foucault's stance, the body is not an individual embodied experience, rather it is disembodied. The body does not exist as an individual, nor is it concerned with the lived experience of functioning within such disciplinary systems. Rather, Foucault's perspective is concerned with how the body is constructed through a political means and exists due to power relations in society (Shilling, 2012). It is these power relations that

deem what body and behaviours are acceptable during certain time periods. Thus, illustrating that the body is socially constructed through regulatory controls.

## Narrative

I initially started this project with the similar intention of those before, to 'give voice' to often silenced groups (Stein & Mankowski, 2004). Typically, this prescribed idea of 'giving voice' in qualitative research reflects a way of making space for those in marginalized groups and giving room for them to speak, representing power dynamics, and the social and political powers in society, who govern whose voice can be heard and what stories can be shared.

However, after engaging with the works of Riessman (2002) I identified that as a researcher, my role was not to 'give voice'. This metaphor of 'giving voice' in qualitative research is a metaphor laden with specific expectations around power and privilege and at times can be detrimental to those in the marginalised groups (Stein & Mankowski, 2004). Rather my role is to bear witness to their story, to allow their voice to be heard and then as a researcher I interpret (Riessman, 2002). The act of telling or re-telling events to someone is an innate part of human life. As humans we are storytellers. The process of sharing a story helps us to make sense of events, it provides order and attempts to bring about understanding to both those who hear the stories but also the narrator. A narrative by nature is a sequence of events resulting with a consequence. The events told in the story, are selected, organized, connected and evaluated to form something of meaning (Riessman, 2005).

Telling stories is an innate part of our human nature, numerous fields of study have adapted the use of narrative to be a form of research - one that turns away from a positivist epistemology and rather turns to a constructionist epistemology. Within psychology we

have adapted the role of narrative and developed what is referred to as narrative psychology. Central to our understanding of narrative psychology is the idea that as humans we engage in what is known as 'order of meaning', everything that is experienced by humans is given meaning by them, this meaning is time specific and relates to the temporality of time (Crossley, 2000) Along with time and temporality, the 'order of meaning' is also concerned with the connections and relationships. Therefore, when we examine the 'order of meaning' we ask ourselves questions such as 'what does this mean?', 'how is this related or connected?' and we place the narrative within a specific period (Riessman, 2005). Consequently, the narrative psychology approach is built around this central idea that there are fundamental links between how we experience ourselves, temporality, time, our relationship with others and morality, in order to understand ourselves and where we should be situated within society (Crossley, 2000). From a research standpoint, narrative psychology provides researchers with a "useful tool which enables us to recapture the way in which selves and identities are grounded in 'cultural' forms of language and sense-making, whilst still maintaining a sense of the 'internal', 'coherent' and 'personal' nature of self-experience" (Crossley,2000, p. 553).

Narrative psychology allows us in research to examine how individuals have constructed specific aspects of their life and how these past events have been integrated into how they construct their lives and identity (Riessman, 2005). Narratives have often existed within an experience in one's life, one where there has "been a breach between ideal and real, self and society" (Riessman, 1993, as cited in Huberman & Miles, 2005, p. 219).

Narrative methodologies can provide a unique perspective around the embodied experience of illnesses, specifically for those whose experience of illness has resulted in feelings of disembodiment. Feelings of disembodiment within illness is particularly common with those who have experienced chronic illness or invasive medical procedures

(Riessman, 2005). Furthering this, narrative methodologies are particularly useful when research is focusing on traumatic life events, as participants often have had trouble making sense of these experiences. As trauma disrupts where at the time of the events the individual was unable to put it into narrative form at the time it occurred results in a 'prenarrative' a way that individuals are able to eventually make sense of such events is by putting it into narrative form (Riessman, 2005). The narrative that consequently develops can be fractured, disjointed and witness to the individual making sense of their traumatic experience. Subsequently, as researchers, it is not our place to fracture these narratives but rather we need to respect the way in which they are shared and analyse it in such a way (Riessman, 2008).

There are several methods for narrative analysis: Narrative discourse analysis, narrative thematic analysis, narrative structural analysis and narrative intersectional analysis. For my thesis I will be using narrative structural analysis

The origin of structural analysis of narrative is situated within the study of social linguistics (Riessman, 2008). The study of linguistics was interested in developing scientific rules for the way in which we speak and convey language. Along with this there was a particular interest in the genre in which we engage, and how these different genres reproduce universal structures of speech, the relationship between speech codes and class structures (Riessman, 2005; Riessman, 2008). The genre in which one engages can greatly alter and change the way in which the narrative is understood and interpreted. Narrative genres can include a habitual narrative (where the same events repeatedly happen causing no peak in action), hypothetical narratives (illustrating something that did not occur), and topic-centred narrative (representing a specific aspect of a past event) (Riessman, 2008). The way in which we share these narratives and the genre they fall

into persuade listeners and readers differently. It is through this persuasion and the threads that pull them together that they become meaningful.

William Labov is a leading theorist in the development of structural analysis of narrative (Riessman, 2005). Labov, argues that a fully formed narrative is composed of six formal properties with each property having a specific function.

1. An abstract- Provides a summary
2. Orientation – This includes the time the event took place, the people involved and what was happening
3. Complicating action – The sequences of events
4. Evaluation- What was the significance and meaning, what is the attitude of the narrator
5. Resolution- What finally happened
6. Coda- Brings the story back to present day.

Each of these properties support the narrator's experiences and helps the individual to make sense of events that took place. Whilst a fully formed narrative includes these six principles, a narrative also consists of the way and the style the story is told. For example, what does a long pause mean and how does this change the string of words being conveyed? Alternatively, has the narrator said something in a whisper or are they yelling? What is the narrator pitch and tempo? Are they stuttering over words or repeating words, how are they conveying emotion when they speak? All these structures used in speech assists to convey the narrative in a specific way (Corbally & O'Neill, 2014).

A structural analysis of narrative does not abandon thematic principles of analysis, it instead expands on and adds to the analytic process. A narrative thematic analysis identifies codes and categories which help to identify differences and similarities between accounts (Harding, 2019). However, with this approach it limits a discussion of the wider

institutional and cultural discourses that exist within the narrative. Alongside this, when multiple participant narratives are grouped into categories and themes, it leaves room for their individual responses to be classified as the same, where they may in fact not fit the typology suggested (Riessman, 2005). In contrast structural analysis of narrative expands on thematic principles, whilst the emphasis shifts to the way in which the story is told. The language used becomes important, the same event can mean different things to different participants. Consequently with structural analysis, you explore the way these same events have been constructed, the sequence of events and the language used (Riessman, 2005).

Using narrative methodologies, specifically structural analysis of narrative allows for the exploration of experiences at both a microanalysis and macroanalysis level. Treatment for AN is often framed by individuals as a journey that is shaped by wider structural forces such as medical policies, eating disorder guidelines and the dominant biomedical narrative (LaMaree et al, 2015). Along similar lines, the use of NGTs, while a medical intervention, is also historically rooted in issues of social justice and politics, therefore this also interjects with the use of NGTs within the medical field (Miller,). Those who have received inpatient treatment for AN have described the experience as being one in which they felt disempowered, disembodied, fear and confusion (Bannatyne & Stapleton, 2017). Thus, utilising narrative structural analysis is an appropriate choice as it allows for both a micro and macro analysis to be conducted of the participants' experience, while also acknowledging and exploring the participants' lived experience of receiving NGTs as part of their treatment.

## Recruitment

Recruitment for this study commenced on the first of November 2019 and concluded on the 30th March 2020. At the time of closing recruitment seven interviews had been

completed. While I was aiming to interview a total of ten participants, I decided that due to the impact of the COVID-19 pandemic it would be in the best interest of those potential participants to close the study early. It was reported very early in the pandemic that COVID-19 has resulted in increases in reported distress and return of eating disorder symptomology for those who have a history of an eating disorder (Khosravi, 2020; Touyz et al., 2020).

During the recruitment period I used a variety of recruitment methods. I created digital posters outlining the topic of my study and the inclusion criteria (see Appendix C). I shared the posters on my personal social media pages (Facebook, Instagram and Twitter). Following this I shared the poster on various Facebook groups; these groups included community pages from various geographical regions in New Zealand, university Facebook pages and specialist eating disorder recovery groups. The eating disorder recovery groups I approached are closed groups that are run by the general public, these groups have numerous rules in terms of what can be posted and discussed on the page. Consequently, I initially experienced difficulty having my posts approved, however, after self-disclosing to administrators that I myself have recovered from an eating disorder I found that they were more reciprocal and willing to share my poster. To reach a wider range of individuals I created a specific public Instagram account where I could share the advertisement. Instagram has a large eating disorder recovery-based community and using specific hashtags that are commonly used within this community I was able to situate my recruitment poster in the Instagram eating disorder recovery community. I approached several specific eating disorder agencies within New Zealand; however, these agencies were often not willing, did not respond or asked for an advertising fee to advertise on their platform. I then placed physical posters around the local universities

and community noticeboards, this was done as a way of reaching those who might not use social media or have access to technology.

After initially advertising to the New Zealand public and getting very little response it was decided that I would advertise outside of New Zealand. Recruitment for outside of New Zealand relied solely on social media posts. Whilst there are advantages to having a homogenous group, due to the strict participant criteria and the use of narrative analysis, the goal of the research is not to generalize nor examine the practices of treatment centres, rather it is to examine the embodied experience of NGTs focusing on the individual's narrative. Thus, having participants from multiple countries creates a heterogenous participant sample in an area of research that is often homogenous. Subsequently, as New Zealand is a relatively small country and treatment options have historically been extremely limited in New Zealand and remain limited to date, it is not unusual for participants to have received treatment overseas.

For this study individuals were eligible if they met the following criteria. Firstly, I aimed to recruit female participants over the age of 18. I want to acknowledge that by recruiting for only females, I in adversely silence the voice of males who have experienced nasogastric feeding. Whilst my attention is not to silence their narrative it was decided that due to the gendered nature of eating disorders and subsequently eating disorder treatment, the male experience of treatment is often significantly different to females (Kinnaird et al, 2019). Consequently, due to the small number of participants in my study, I would unlikely be able to explore the male experience of this treatment in the necessary depth and risk having the male experience overshadowed by the female experience which is what frequently occurs (Kinnaird et al, 2019). This often leads to further stigmatizing views of male eating disorders.

Potential participants were required to have received a diagnosis of AN; I understand that within research, those with eating disorders and general society, AN is often placed in an idolized position with more positive connotations associated, whilst other eating disorders (bulimia nervosa, binge eating disorder, avoidant restrictive food intake disorder, other specified feeding or eating disorder) are often viewed as 'lesser' or have more negative connotations attached. Moreover, I recognize that there is a sense of 'privilege' attached to receiving a diagnosis of AN over a different eating disorder, this 'privilege' is reflected in how eating disorder treatment is geared towards 'treating the anorexic patient'. It is not my intention in recruiting only those with a diagnosis of AN to contribute to the hierarchy that exists amongst eating disorders. Rather, within eating disorder treatment, NGTs are primarily used on those with a diagnosis of AN.

Finally, the inclusion criteria outlined that potential participants need to be discharged from eating disorder services and have not been inpatient or received a NGT since October 2017. It was decided that having a minimum of two years since last receiving a NGT would assist in reducing any potential distress that could result from discussing their experience with a NGT. In addition, potential participants needed to consider themselves in a place of stable recovery. The wording of a stable place of recovery was intentional, keeping it aligned with a social constructed epistemology and also recognising that as AN is often viewed through a biomedical paradigm, a stable place of recovery reflects the idea that recovery is a subjective experience that is not necessarily something that can be determined through the absence of eating disorder symptomology (Rinaldi et al, 2016). Therefore, through using this wording it allowed for inclusivity to those who may not be recovered by medical standards, but in a place where they feel they can speak about their experience, without jeopardising their own recovery.

## Participants

I had a total of 14 women contact me, three of these women were unable to participate in the study as they had recently been in treatment or were currently still in treatment. Four potential participants decided not to follow through with the interview. Therefore, for this study I interviewed a total of seven women. The women interviewed ages ranged from 19-years to 29-years, with a mean age of 24-years. Amongst the participants the age at which they received a diagnosis of AN ranged from 10-years to 21-years, with a mean of 14.7-years. In contrast the age at which the participants received their first NGT ranged from 10-years to 22-years with an average age of 15.8-years. At the time of the interview there had been an average of 8-years between the time of receiving a NGT and participation in the study. However, the range of time surpassed from receiving a NGT to participating in the interview was 4-years to 16-years with a mode of 4-years. As the study was opened internationally, I interviewed participants from New Zealand (3), Australia (2), Germany (1) and England (1). However, the countries in which the participants received their NGT as part of their treatment included New Zealand (3), Australia (3) and England (1). It was decided that information related to participant ethnicity would not be recorded.

All participants received a NGT within the context of inpatient treatment for AN. However, the facility type differed between participants and even across participant experiences. This meant that some participants had received a NGT within the context of both private and public hospitals. Along with this they received NGTs within the context of medical wards, general mental health wards, adolescent locked mental health units, paediatric wards, specialist eating disorder wards and general wards. With this there was a mix of participant experiences with them receiving treatment as either voluntary, under

the relevant country's mental health act or as child where they were unable to give consent.

Overall, the participants' stories have varied drastically despite having such a strict participant criterion. Therefore, with the current participants I achieved the goal of having a heterogenic sample.

## Narrative interviews

My interviews were centred around narrative principles; therefore, the interview questions were composed of open-ended and semi-structured questions. As the interview topic is one that had potential to cause distress or bring up painful past emotions, my interview approach was guided by several considerations:

- Create a warm and secure environment
- To minimize power differentials between researcher and participant
- To attend to the interviews with a non-judgmental attitude
- Create a collaborative process
- To go at the participant's pace, allowing for breaks
- To be flexible with my questions and allow for the interview to flow naturally rather than keeping stringently to my interview questions
- To be able to hold their emotions during the interview

As the topic of nasogastric feeding is often experienced through a power differential when the individual does not have a say in this aspect of the treatment, along with the potentially traumatizing nature of this experience, I held these considerations from my first interview. I was aware that my position as a 'researcher' could mirror a power differential and thus it was important for me to give the participant as much control as possible and allow them to tell their story in their words and order.

The practicality of holding these considerations in place started when the participant made their initial point of contact. Interviews were arranged either via text-message or e-mail. While some participants were comfortable to make an interview after reading the initial information sheet, others expressed their wish to participate but acknowledged their anxiety around either their suitability to participate in the research or alternatively anxiety around the unknown aspect of the study. In order to ease anxiety, this meant that for some participants I would send them the questions beforehand and explained in detail what to expect in the interview, the process of it and what would happen.

Participants who lived within the Auckland region were given the option to decide where they would like the interview. While interviews outside of the Auckland region were conducted via Skype, Zoom and Facetime, depending on what the participant felt most comfortable with.

Prior to the start of the formal interview, I would spend time talking with and getting to know each participant. During this time, we would go through the informed consent and participants had the opportunity to ask questions relating to the study. It was often during this time participants would enquire why I had the interest in the topic and asking if I had my own personal journey with an eating disorder. When the participant indicated that they were ready to start the interview, it was at that point I would turn on the recorder.

I found that while each participant appeared comfortable talking prior to recording, the initial few minutes of recording often seemed disjointed. To ease participants into the idea of being recorded I started by asking some basic demographic questions focusing on their age, gender, age of first NGT and what diagnosis they had received. I found that starting by answering some basic questions about themselves this often shifted the nerves and allowed participant is the chance to get comfortable.

I started each of the interviews by asking if they would mind telling me about their experience with a NGT. I suggested they could start where they would like, some people find it helpful to start at the time the NGT is inserted while others feel comfortable starting to the lead up of getting the NGT. I reinforced that where they started was up to them. I continued to say that I will let them talk freely and will not interrupt them but at the end I will ask you some follow up questions about their experience.

The length of time participants talked for varied with some interviews between 30-minutes to 90minutes. During the interview, a range of emotions came up for participants. Though some participants seemed to disengage during the interview, providing minimal eye contact, no body movement, no change in tone when speaking or stuttering, others would go through a range of emotions, participants had the option of pausing the interview if they wished, which occurred a couple of times throughout the process. Others preferred to push through saying that they are okay with the emotion they are feeling and though it brings up painful memories, they do not feel distressed by them.

After the participants shared their story with no interruptions, I would follow this up with questions and clarification around their narrative. Following this I had a series of semi-structured question that I asked each participant (See Appendix F).

Once the interview had ended and I had turned off the recorder, I spent some time at the end with each participant. I was aware that for some of the participants this was the first time they had shared their story, for others it brought up memories they had not thought about in a long time. So, I spent some time with them, checking in how they felt, if they had any concerns and if they were okay. For some participants this meant reflecting on what they had shared, for others it meant acknowledging the feelings and reassuring I did not view them in a particular way (i.e. a lot of shame was discussed in relation to

behaviours they engaged with when they were struggling with anorexia). For other participants it was about having a chat and just bringing them back to the present. It was important at this time that I did not rush the end of the interview and rather allowed for them to say when they were ready to leave. Following this, each participant was e-mailed a list of supportive helplines suitable for their country of residence (Appendix G)

## Ethical Considerations

All data collected and analysed was conducted in accordance with the principles of Massey University Code of Ethics and has been approved by Massey University Research Ethics Board (NOR 19/51) (Appendix I).

In undertaking my research, the key ethical issues pertained to gaining informed consent, confidently and managing potential distress. When it came to informed consent from participants, this looked differently for different participants. When each participant made initial contact with me I provided them an overview of the study and sent them the information sheet (Appendix J) and consent sheet (Appendix K) to look over. After participants had read both of these, they were able to ask questions in regard to study. Following this, if participants were wanting to take part in the interview, we then scheduled a date. If participants were located overseas and the interview was therefore conducted over Zoom, Skype or Messenger, the consent form was signed and sent to me prior to us meeting. We would then meet on the participant's desired platform and I would go through the consent form and information form with them again, giving them another chance to ask any questions. If they were then happy to proceed, we started the interview. If the interview took place in person, we would then go through the sheet together and then they would sign the consent sheet in person.

For some participants the prospect of taking part in a study was anxiety provoking due to the unknown factor. For these participants, I would provide them with a general layout of how the interview would go and provide them with the standard set of questions asked. This process would take place prior to the signing of the consent sheet. Providing this information both supported the participant in making an informed decision about participating in the study, while also minimising potential distress.

In terms of confidentiality, this was particularly important to uphold within this study due to the small amount of people who do receive NGTs, the limited eating disorder services and how small eating disorder communities are. As a result, along with the usual practices of providing pseudonyms for each participant, participants' ages have been sorted into age bands and the participant's state, location or treatment centre have all been excluded from the study. Only general geographical regions are provided. Ethnic information has also been excluded from the study; this is a decision made in collaboration with Massey University School of Psychology cultural advisor. I do acknowledge that there is some benefit to representing marginalised groups in research, but in the context of my research, I did not want to risk further harming marginalised groups by including ethnic information. Specifically, as those who predominately access treatment for AN are white, those belonging to marginalised ethnic groups would be more easily identified and therefore risks their right to confidentiality. Finally, as I would not be doing anything with the ethnic data outside of reporting it, this would not benefit the marginalised group in any way.

The third most pressing ethical issue my study faced was the potential for distress for both the participants and researcher. The risk for potential distress to participant is something that has been well documented in research, this is particularly true when the research involves highly emotional topics. As indicated by previous qualitative research on AN,

my research was identified as being emotive as it was potentially examining an experience that could be classed as traumatic. Consequently, several steps were taken to ensure the safety of participants. Following the recommendations of Burke Draucker et al. (2009) I developed a distress protocol. Burke Draucker et al. (2009) identified that there were several steps researchers could take in decreasing the potential of distress: 1) employing interviewers who are trained to handle psychological distress, 2) monitoring of participants emotional reactions, 3) providing breaks during the interview, 4) debriefing and 5) providing information on available services. Within my research I made sure to meet each of these points. I also have a history of working in mental health, specifically with women who have experienced some form of trauma, emotional deregulation or distress. Within my job, I have completed numerous trainings in working with trauma and de-escalation of high emotional arousal. In terms of monitoring of participants' emotional reactions throughout the interviews, I monitored for change of tone, body posture, signs of dissociation and deregulation and if I noticed these signs during the interview, I would suggest breaks. Participants were also free to indicate if they would like a break. At the end of the interview, I checked in with the participants, I asked how they felt, identified that it could bring up some difficult feelings and emotions. Often, we would spend around 10-15 minutes just talking at the end and bringing participants back to present, acknowledging their emotions and feelings and often offering reassurance or validation. It was common during this for feelings of shame and embarrassment to come up for them. I would tell them that we can spend some time talking and when they were ready we could end. This allowed them to be in control and illustrate to them both respect and care for the experience they had shared with me, as well as respecting them as a person. Finally, at the end of the interview, I provided participants with numbers to the relevant geographical helplines.

In addition to potential distress to participants, there is also a level of potential distress to the researcher. Stahlke (2018) discusses the multitude of ethical risks qualitative researchers face that pertain to them personally, during their research. In conducting my research, I found myself hearing distressing stories shared by participants, meaning I was supporting them with their emotions while simultaneously managing my own. In learning to manage my own ethical risks I engaged in a series of practices post interviews. Initially I would start by debriefing with my university supervisor directly post interview. I found that while this was helpful in discussing aspects such as how I managed the logistics of the interview, it did very little for actually debriefing on the interview and the emotional side of it. Rather with some participant narratives, two to three days post interview I would find myself to start to ruminate. As a consequence we changed the debriefing format with my supervisor. Directly after interviews I would send her a brief summary, and then we would meet in person two to three days post interview. This would often allow me time to process and untangle the interview in my mind. Along with debriefing with my supervisor, I also engaged in my own personal therapy where I could discuss, when needed, aspects of my research. While I engaged in therapy, the point of discussion in therapy was not focused on what was shared with me in interviews and rather addressed feelings of counter-transference experienced in my research along with memories triggered by the interviews that I had previously forgotten. In engaging with both of these practices, I found I experienced minimal distress relating to my research and was able to remain present for the duration of my thesis.

## Analysis

In analysing the data I followed the steps laid out by Riessman (2008) on structural narrative analysis. I started by hand transcribing the interviews. It was during the transcription stage each participant was provided with a pseudonym. During the

transcription process any identifying information was removed. I developed a series of shortcuts during the transcription stage to reflect changes in tones, pauses, drawn out words, the use of sarcasm, laughter and so forth. Following the initial completion of the transcription, I then listened to the audio again, with the transcribed documents in front of me as this allowed for assurance that nothing was missed before I transitioned to the analysis stage.

I printed two copies of the transcriptions off; one copy of the transcription was used to complete the microanalysis while the second copy was to complete the macroanalysis.

I started with the microanalysis, reading through each transcript and writing in the margins any initial thoughts and feelings I had. Following this I went through each individual transcript and looked for any re-emerging codes or patterns in the text. Following the identification of codes and patterns, I created an Excel spreadsheet as a way to organise the data. On the top I had each pseudonym and then down the side I had the following headings: Abstract, Orientation, Complicating action, Evaluation, Resolution and Coda. These headings were outlined in Riessman (2008) steps. As the experience shared for participants was considered to be traumatic, it meant that as a researcher I was working with a prenarrative and that the way the experience was told did not necessarily follow a sequential order. Organising it into Labov headings (Riessman, 2008) steps allowed me to make sense of the data, while also comparing for similar themes and patterns across each part of the narrative story.

After I had a complete data set that had been sorted into Labov six headings as outlined in Riessman (2008), I then went back to the transcripts. This time I was looking at the language participants used in greater detail. While structural analysis allows for attention to be paid to the macroanalysis, structural analysis also relies heavily on linguistic

features to make sense of how the information is being conveyed. I therefore went back through the transcripts this time focusing on the words used. I categorised words into emotions, patterns of speech (i.e. elongating words, stuttering, pauses, word fillers) , the language participants used to position themselves within their own narrative (i.e. the use of first person active voice or third person passive voice), the use of metaphors and the use of trauma linguistics (Busch & McNamara, 2020). Examining the linguistics to this extent allowed me to develop a deeper understanding of how the participants situated themselves and how they embodied their narrative.

Once I had completed the microanalysis, I conducted the macroanalysis. With the macroanalysis I went back through the transcripts, this time writing notes on the side pertaining to how society, policies and politics have influenced their narrative. Furthering this, I went through and then identified the numerous discourses participants were drawing on to construct their narrative and how this in-turn influenced their experience. Finally, I went through and looked for the discussion of power dynamics and how the influenced how the participants situated themselves within the story, their reactions and linked this to how it related to the wider societal and political discourses.

After completing both the microanalysis and macroanalysis I then compared the themes across each participant to see if there was a common theme or pattern with how each of the narratives were constructed. This resulted in the development of an overall narrative, where clear patterns of similarities and differences of experiences for each area of Labov steps (Riessman, 2008) became apparent. Finally I went back through the data looking for quotes to frame each of the different narrative points and themes that existed in each section.

Once the analysis was completed the findings were placed in sequential order, corresponding with Labov steps (Riessman, 2008). The findings identified five narrative points and in each narrative point were several themes relating to the participants' experience.

## Reflexivity

A critical aspect of qualitative research is the ability to reflect on my research and how my being has shaped, interacted and influenced my research. The process of self-reflection is something I engaged in early in the research process. As I started to interact and read literature, countless notes were made on margins with ideas, thoughts, connections and my own feelings about the work. This provided me with a starting ground for inquiring how my position could influence and shape the research project, I grappled initially with identifying where my epistemological beliefs are situated, with conflict around how knowledge is conceptualised.

My process of reflexivity initially started with a journal, a book where ideas were written, arguments could take place and I could write down my queries. As my research progressed and I developed the interview questions I found myself reflecting on if the questions are answering my personal queries or the research aims. I was aware that due to the personal nature of my project, it was important to not tangle up my own experiences with my research. This often caused for me to step back, reflect, journal and discuss with my supervisors.

As I started interviewing, the way in which I engaged with reflexivity changed. During each interview I made note of how I was feeling, how did my emotion shift, how did the participant's emotions shift. I reflected these in journal entries post interview. I queried why these shifts could have occurred and made use of both supervision and therapy to

discuss the impact of hearing other accounts, which at times were traumatic. I reflected on my own ability as a researcher, at times feeling lost in the process, other times curious but feeling ill-equipped to pursue certain questions further, but recognised both my limitations of being a researcher and resist the urge from approaching the topic from a therapeutic standpoint.

I found that as the interviews progressed into the transcribing, my method changed from being journal based, to engaging in art-based mediums. I create a series of photos reflecting how I felt. I drew when I had feelings or thoughts that my words did not seem to capture effectively in my reflexive journal. I embodied the experience as I found solace in moving my body. Often the process of words did not suffice.

At the analysis level, I drew once again on reflections. I went through the transcribing highlighting areas that stand out, reflecting on areas that I found challenging. Where these were experiences that were so similar to mine, I worried about the integration of my own personal experience or passages that were so far from my experience or it challenged my own belief and positioning on eating disorder treatment.

Throughout this process I kept an honest conversation with my supervisor, at times reflecting on my own experience and how this differed or was like my own.

### *Positioning myself*

A critical aspect of qualitative research is the ability to reflect on my research and how my being has shaped, interacted and influenced my research. My research is one of a deeply personal nature, having had my own history of AN where my treatment included the use of multiple NGTs. While it has been eight years since I last received a NGT, admitting I have received a NGT is still a point of innate shame, fear, guilt, privilege, sadness and anxiety. Admitting both my history of AN and speaking of my treatment

experience within an academic setting further perpetuates these feelings. However, the deeply personal nature of having received a NGT was also to a degree an asset to my thesis, while my 'insider' status was not of importance to all participants within my thesis, with those who inquired, it allowed for a shared language to be developed and a shared understanding.

Engaging in a topic that was so personal has been a journey. When I first started my thesis topic, I found that while I was willing to disclose my insider status to participants within my study, I had specific fears around the university or specifically those within academia finding out and deeming me unfit to study my topic of choice. This fear likely derived from the power dynamics that I experienced in hospital and have since unconsciously continued to live under; the idea of regimented control that is experienced in eating disorder treatment, where your voice or lived experience is considered to be 'other' to that of a professional. I engaged with this discourse for a long time after treatment, often taking the position of a passive individual within my own body in attempt to re-negotiate the idea that my body was docile rather than mismanaged.

While I would like to say that my first attempt at disclosure over my own personal experience within a university setting was one that was held safely or received positively, I instead found myself re-engaging with a similar power structure, where my body or my existence as someone with a history of AN was one that was a unacceptable reality. My disclosure was received with the suggestion that in order for me to manage the thesis process, I should seek therapy for the duration of my thesis and then adding to this, I may not have the emotional resilience to carry out my topic. This sentiment, though the individual may have meant with care, translated to me that I was once again being placed in the sphere of someone in a position of power, placing me and my experience in the position of being an 'other'. This idea is something that is often reflected in eating

disorder literature, where those with eating disorders experience the feeling of being treated as if they were an anorexic rather than a person. At that moment, this is how I felt, with my fears being confirmed, that having lived experience presented me in a pathologized light, where I would not have the insight to manage my own body.

Furthering these fears, I worried how my position of someone with lived experience, researching in the eating disorder community would have my research diminished, and open me back up to feelings I felt in treatment; feeling of disempowerment, less than human, and just an anorexic. I worried that by self-disclosing, I would open myself up for a similar level of criticism and control over my life that had previously dictated my life. Along with this, I worried that my history would overshadow the worth of the project and the work I produce would be considered lesser than. I realized that although I held a lot of fear leading me to want to remain an invisible party within my own work, it is the reason I ultimately wanted to engage in a topic that had once held trauma for me.

As my thesis progressed, I have found that my fears and perceptions around self-disclosure and my position as someone with a history of AN has changed. Though the objective of my study was never to bring light or share my own story, what I have found is that my study has been transformative in how I have experienced and view my own treatment and changed how I now relate to AN.

My thesis gave me a space for the first time to explore my own experiences of anorexia from a different perspective. It gave me the time to explore how treatment had impacted me, changed me, and acknowledge really for the first time my own treatment experience. Like my participants, I found myself exploring the dialectal of being thankful for treatment and the intervention and recognising that it was also harmful, while also struggling with feelings of failure for accepting a NGT.

Following this, though there are undoubtedly power dynamics within academia that at time I experienced as a sort of transference between experiences, it also allowed for different outcomes. A particular instance, where I met with the ethics board to get ethical approval for my project, sitting around a table at one end with multiple individuals in a position of power who decide if your project has ethical clearance, mirrored to me an instance in my eating disorder treatment, where I sat alone at a table surrounded by health professionals each of whom was speaking of me but not to me about what would happen with my care. This experience for me reflected a similar power dynamic, where I once would have sat silent, where this time I was able to speak, advocate and at times slightly argue. It was in this experience, I for the first time felt that I had a voice.

As my thesis progressed, I found my emotions waxed and waned. I found that engaging in literature often brought up the more intense feelings and questions. Despite constructing my thesis from a socially constructed perspective, I was often still relating my own experiences to a positivist epistemology where I understood my own story through a psychological discourse. This often created a sense of conflict, as there was a sense of safety through engaging in a psychological discourse where my understanding was posited on specific ideas, where examining anorexia and treatment through a socially constructed epistemology, created a sense of conflict.

Though the engagement in literature was confronting and I found my own story at the forefront of my mind, when it came to the interview I often experienced as if my own story was non-existent. I listened to the narratives my participants told me and reflected on these. After interviews as I reflected on the experiences, I engaged in journaling, creating photographs and painting as a means of processing what I had been told. Often the narratives shared left me feeling angered, sad, confused and feelings of injustice for the power dynamics these women experienced in a place that was meant to be safe. I

found that I held these feelings in a different way then I held my own experiences and to a degree, it was easier to feel the emotional pull that came with hearing traumatic narratives than it was to feel this way about my own.

I am still not sure if I am entirely comfortable with sharing my experience of having experienced AN and nasogastric feeding as part of my thesis. However, it is an integral part of this thesis story. Had it not been for my own experience, this thesis would not have been conceptualised and if it had, I would have approached the topic from a very different perspective and the narratives that were shared by participants would likely be understood and analysed very differently. It is a difficult thing to discuss the power you experience in treatment, when you are taught that you are privileged to be receiving it and furthering this, that you deserve what occurs in a treatment setting. Having had anorexia has changed the way I interact with those in power, it has also changed the way I interact and perceive my own body. In submitting this section, I realise that the fears I have around having those in a position of power read my disclosure; I cannot control how they react, their thought process or perception of me. They may view my thesis or research as being less than, because of my own experiences. The way I started the thesis with the idea that my body is mismanaged, I have realised that it is not the case and so I have come to the conclusion, that though I may not be comfortable, I am okay with it.

# Chapter Four

# Findings

As my finding section takes on a narrative form, my findings section is laid out in the following manner. The introduction to the finding section introduces you to each participant and provides some context of their experience. This section functions as the orientation as outlined by Labov's steps for narrative analysis (Riessman, 2008). Following the introduction of participants, I will discuss five narrative points that are significant to the participants' stories and the unique themes within each of the narrative points. The five main narrative points are as followed; insertion of the NGT, types of nasogastric feeds, living with a NGT, "am I sick enough?" and resisting the NGT. When examining the five main narrative points, I will examine specific elements from the participants' stories, using quotes as a base and then providing an interpretation through the incorporation of theory and the micro and macro elements of each story. Following the five narrative points there is then a section on reflections, this section concludes each participant's experience with having a NGT. This reflection section functions as the Coda as outlined by Labov's steps (Riessman, 2008). Like the introduction of the participants, this section will not incorporate theory or interpretation and rather is a way of summarising their experience.

## Participants

Seven women were interviewed for this thesis. In order to protect their identity, they have each been given a pseudonym

Abby Lockhart: Received multiple nasogastric tubs when she was under the age of 12, in telling her story she described herself as going from a "fully functioning child" to less

than a month later when she developed AN and was on "death's door", she was quickly admitted to  hospital where she received her first NGT. While the diagnosis of AN happened quickly, she reflects that prior to the onset of AN she struggled with more orthorexia behaviour which had been managed at home, until she then went on to develop AN.

Carol Hathaway: Received one NGT between the ages of 18-24.  In telling her story, she reflects that while her experience with AN was diagnosed at the time of receiving a NGT, it had been going on for much longer and there had been a lead up to it. Carol experienced a couple of admissions and it was on her second admission she received a NGT. Carol worked collaboratively with her treatment team, this overall allowed for a more positive experience with her treatment.

Elizabeth Corday: Received one  NGT between the ages of 18-24. In telling her story she reflects that she had initially been diagnosed years earlier with AN, but had never received treatment for it, as it "was a side effect of anxiety, so it wasn't your typical eating disorder". Her admission into an inpatient ward was not initially for AN, but rather for suicidal ideation. It was on the ward she stopped eating to hurt herself, at this time she was then diagnosed with AN and received a NGT.

Kerry Weaver: Received one NGT between the ages of 13-17. In telling her story she states that she had previous admissions where she had not received a NGT, but it was a lack of beds that led to her being sent to a different facility than usual that resulted in her receiving a NGT. She reflects that this hospital from her perspective had a lack of training in eating disorders: "If I had been admitted to the hospital where I knew people they wouldn't have done it, but, in the circumstances, without their eating disorder knowledge, they thought they didn't have a choice".

Lucy Knight: Received one NGT between the ages of 13-17. In telling her story she describes herself as being in a zombie-like-state, not knowing what was going on and lacking nutrients. Lucy received her NGT on the third day of her hospital admission.

Neela Rasgotra: Received multiple NGT when she was under the age of 12. In telling her story she discusses how it started off with restricting her intake, being anxious and struggling with obsessive thinking. This occurred within the context of "stuff happening in my personal life" and resulted in her restriction becoming more severe. Once she started restricting severely it was only a couple of months before she was hospitalised. She received a NGT on the first hospital admission, then again on the subsequent hospital admissions. For Neela, she described herself as being compliant with the first admission, but with subsequent admissions something "switched" and she is unsure why, but she started to resist treatment.

Susan Lewis: Received multiple NGT between the age of 18-24. She had a previous admission for medical stabilisation but reflected that it was not taken seriously at this stage. The following year Susan was admitted again, and it was at this hospital she received a NGT. Over the next few years Susan had multiple admissions and received numerous NGTs.

## Insertion of NGT

The insertion of the NGT was described by many as an experience in which they lacked control, autonomy and consent over their own bodies. This experience was amplified for participants who were unaware of how the NGT would be inserted and this created greater levels of distress and reaction from the participant. Furthering this, participants used more emotive language to describe their feelings and the related physical sensations when they had not given consent for the insertion of the NGT. This contrasts with participants who

provided consent where they acknowledged a level of discomfort associated with the procedure but experienced the insertion as being a collaborative process.

Similarly, participants who had reported that they were unaware of the nature of the insertion process had longer narrative passages, repeated words, and used more sentence fillers (such as "um") in contrast to participants who felt they were well informed of the process. Of the seven participants interviewed, two expressed that they had been informed of what would happen during insertion. The remaining five participants were not given any information on what would occur during the medical procedure.

Of the seven participants interviewed, Elizabeth experienced her first nasogastric insertion under the mental health legislation that removed her ability to give consent and reflects on this experience:

*" They had three nurses from the ED (Eating Disorder) ward come into my room, they made me sit on a chair in the middle of the room, and they um, I had a cup of water and I had to drink the water as they inserted the tube. I didn't fight at all. I had no idea what was going on, or how this worked, so I just let it go in"*

Within the passage of text, Elizabeth utilises several linguistic features that suggest a passivity in her own story. While on surface it sounds as if Elizabeth was taking an active part in the experience as she continuously uses 'I' statements, the repetitive and short nature of these 'I' statements frame her position as one of non-response or anti-response (Latorre Gentoso, 2012). Furthering this, as Elizabeth positions herself within her narrative as passive, her tone remains slow and monotoned, while she physically positions herself to face away from me as I interview her, and she appears disengaged while speaking. This body language in combination with the continuous use of anti-responses

or non-response are inductive of a trauma response as she draws on trauma linguistics to share her story (Latorre Gentoso, 2012).

In Elizabeth's story of insertion there are multiple layers of power and power dynamics at play that are framing her experience. As Elizabeth stated, she has been placed under the mental health legislation. In being placed under the mental health act, Elizabeth experiences what Goffman (1961) termed as being psychiatric institutionalization. Goffman stated that psychiatric institutionalization is the representation of psychiatric hospitals having similar characteristics to prisons, where those within the setting were subjected to stigmatizing practices, experience a restriction of freedom and have their social roles taken away (Chow & Priebe, 2013). One of the four properties of psychiatric institutionalization is the dependence on legislation and policies regulating care which allow for the individual to receive specific treatment, despite not giving their consent. In the case of Elizabeth, this is her experience with the mental health act.

The mental health legislation in Elizabeth's situation is one form of power at play that positions her as being passive. Elizabeth's lack of power was further asserted as she discusses the experience of having three nurses brought in and then having the insertion take place in the middle of the room on a chair. The excessive use of nurses along with the placement of a chair functioned as a way of further demonstrating Goffman's (1961) theory of psychiatric institutionalization at play. Furthering Goffman's (1961) theory, this is also a demonstration of the re-making of a docile body; Elizabeth was placed in a position of having observation directly placed upon her during a medical procedure, where the two extra nurses place her in a position of having to engage in self-monitoring (Foucault, 1975), her response to reduce the punishment that may be inflicted on her body if she resisted. In this situation, while it may seem as if she was not active in this situation, rather the act of passivity was a response in which she was able to protect herself in a

way that she needed from the greater power dynamics she was experiencing during the insertion process (Latorre Gentoso, 2012). If this perspective was to align with a psychological discourse, Elizabeth's actions along with her language could represent a form of either depersonalisation or dissociation, which is a common response from the psychology discipline to trauma experiences (Lanius, 2015).

In contrast to Elizabeth, Susan was on a medical ward and while she at the time of insertion was not under a mental health act, fears around being placed under a mental health act were pronounced for Susan. Susan describes how she was aware that if she reacted during the insertion process this would result in force being used during insertion. Subsequently, Susan engaged in self-monitoring (Foucault, 1975) and found the experience to be one that produced fear and anxiety.

Susan comments on the complications that occurred during her insertion process:

*"They managed to place it and make it come out through my mouth which was even more terrifying, so they had to pull it out, they put it in then had to pull it out, I think because I was panicking. Nobody told me to calm down. The way it works in <country> is if you refuse, they will just come and hold you down. So, I was trying not to refuse and trying to remain calm, which wasn't exactly helpful".*

As Susan talked about her experience, she constantly refers to the NGT as 'thing' or 'it'. This repetitive pattern of speech is an example of how Susan used specific language to distance herself from the experience. The use of distancing language can be adaptive for coping with events that created feelings of emotional distress, and the use of distancing language can also reduce longer term negative emotions towards the experience and allow for self-reflection (Ayduk & Kross., 2010).

Susan expanded on her experience, stating:

*"Don't give me a nurse who doesn't know what she's doing and so it comes out through my mouth because, because, what, how, like in the tube, there is a wiring to guide it, like what the hell did you do, she put it in and tried to shove it in, so I can't have them placed on the left side of my face. So, they tried to do that for 5-minutes, so there was blood"*

As Susan progresses through her experience of insertion, the linguistic features she uses changes. This ultimately conveys a layered and shifting experience. While in the introduction of her experience she uses distancing language, where her tone was relatively stable throughout with minimal emotion, as she explains the difficulties associated with insertion, her tone changes to reflect anger and heightened emotion. During this state of heightened emotion, Susan changes from telling her story in past-tense to present-tense, this change in tense reflects a change from self-distancing of the event to a self-immersed perspective, which creates a more emotional reconstruction of the experience (Ayduk & Kross, 2010). Adding to the change from self-distancing to self-immersed perspective, Susan frequently utilised sarcasm. This was typically geared towards herself and reflected either anger towards the staff: "which is great", or anger towards her eating disorder: "anorexia is just great". The use of sarcasm in this situation illustrates the incongruity between the situation and what is said (Skalicky & Crossley, 2018).

Though Susan demonstrates anger towards her experience, she also indicates a sense of self-blame for how the insertion process went, as she wonders if it was due to her panicking. Self-blame in this circumstance functions as a further coping mechanism that reflects a lower level of self-compassion and highlights the uncertainty of the situation (Balzarotti et al., 2016). Susan, throughout her narrative of the insertion process, oscillated between a self-immersed perspective and self-distancing perspective, as well as emotional responses, specifically anger, sarcasm and then the use of self-blame. These

linguistic strategies build a wider narrative of Susan's experience, one where while she struggled with feelings of anxiety and fear. This experience of insertion was not focused on the fear of weight gain as previously cited as reasons for fearing NGTs (Neiderman et al, 2001), but rather reflects the wider fear of the power dynamics that exist within the treatment for eating disorders, where non-compliance or even reaction to an experience that causes feeling of discomfort could be considered as treatment resistance and could result in being placed under the mental health legislation.

When we examine the wider discourse surrounding Susan's experience, she engages with her country's health policies as a way of understanding and explaining her thought processes and behaviour. In discussing her country's policies, she specifically discusses the use of force and the mental health legislation as a potential part of eating disorder treatment. These policies that allow the use of force and the mental health legislation convey how hospitals are a setting for psychiatric institutionalisation (Goffman, 1961). Though literature has argued that mental health has gone through a period of deinstitutionalization which in turn influenced the public policy around mental health treatment (Cabral da Silva & Lima, 2017), Susan's experience reflects how policies in treatment still uphold the principles of psychiatric institutionalisation.

In contrast to Elizabeth's experience of having a NGT inserted, Kerry positioned her narrative from a self-immersed perspective (Ayduk & Kross, 2010). Constructing a narrative through a self-immersed perspective shifts the focus to an emotional construction (Ayduk & Kross, 2010). Kerry starts her experience by describing the moments before the NGT was inserted:

*"I remember they took me to a room and talked to me just before it was about to happen, they weren't very compassionate at all. Like when they had trouble, they just kept trying to shove it down"*

Kerry uses a similar linguistic strategy to Susan as she describes the NGT as 'it' which reflects a method of distancing herself from the NGT. However, while Susan proceeded to engage in a self-distancing linguistic strategies, placed the blame on herself and postulated that the difficulty with insertion reflected her panicking, Kerry focuses on how the staff showed a lack of compassion, and followed this up with the example of the staff having trouble inserting the NGT. Kerry postulated that it was to do with a lack of compassion; utilising the word "shove" reflects a specific type of force was used during the procedure and carries more emotion with it. Kerry discusses both the clinical nature of the staff and lack of compassion. She reflected on how she wanted her mum as a support person but staff would not allow this. Kerry attributed the lack of support during the insertion process as contributing to her distress during the insertion.

In contrast to the six other interviewed participants who did not mention if they had a parent or support person present during the insertion process, Kerry reflected on not only the fact she wanted her mum present during this process, but also on the fact that she was denied this and how this further perpetuated the distress. Consequently, during the insertion Kerry called out for her mum and tried to leave the room to get up, but the staff reacted by holding her down. Resistance to nasogastric insertions are pathologized by those in the medical community and seen as reflecting diagnostic symptomology (American Psychiatric Association, 2013). For Kerry as she reflects her experience of not being allowed her mum, she hypothesizes:

*"Maybe the reason they didn't let me have someone as they thought I was the problem or something"*

This reflection sees Kerry engaging in a wider child-like discourse that is commonly experienced in treatment for AN, where the individual is often punished or talked down to as if they are a child.However, Kerry's experience expands beyond this reflecting the wider power dynamics, where she was both denied support during the medical procedure, reflecting the stigmatised position those receiving inpatient treatment for mental illness face (Goffman, 1961), while also illustrating further power dynamics within the treatment, where physical force can be asserted against the body in order to make it docile (Foucault, 1975).

Therefore, while Kerry wonders if she is the problem, it is the larger power dynamics at play reflecting the political nature of the body. This political nature is where the body acts as a political investment designed for economic purpose and when the body does not act in a way where it will produce economic output, it allows for the body to become a subjected body (Foucault, 1975). Consequently, the body is seen as needing correcting to become docile so that it can be productive. Therefore, as medical professionals hold power over those with mismanaged bodies (Frank, 1995) they enforce force over the body as a way of correcting the body into having economic purpose (Foucault, 1975). As Kerry wonders if she is the problem, what she is touching on is the complex power relations the body is tied up in.

Abby and Neela were both under the age of 12 at the time of their first NGT insertion. As a result, they are the only two participants to have received treatment on a children's ward. This change in ward created a striking difference from the other participants' experiences.

Neela reflects on her initial insertion stating:

*"I remember the first time it was inserted, I didn't struggle at all, there was no, you know, it was this is going to happen, I think they used that NG tube as well as me eating to kinda, you know, get up to , sorta place where I was medically stable"*

Neela draws primarily on a biomedical discourse, discussing the purpose of the NGT was to get her to a place of medical stability. In engaging in a primary biomedical discourse Neela is demonstrating how in order to understand her own experience she has engaged in the medicalized language which results in the narrative of embodiment being lost (Frank, 1995). While Kerry and Susan used emotive terms such as "shoved" or referred to the NGT as "it" or "thing", Neela directly identifies the NGT by its name. This therefore holds a different meaning for how Neela has understood and conceptualized her experience. Neela's description of her first insertion is brief and shared with very little emotion. Later, Neela positions her nasogastric experience from a very different position.

In contrast, Abby was the only participant who was not awake during the first insertion and experienced her initial insertion via sedation. It is unclear if sedation was used due to her age, difficulty with insertion or distress associated with insertion. Consequently, when Abby shared about her first experience of nasogastric insertion, she positions her narrative around the moments before and then the moment after the NGT was inserted. Though it may be perceived as being more humane to sedate an individual for the insertion process, Goffman (1961) positions the use of sedation as a tool of the psychiatric institutionalization.

Abby reflects on the moments she found out she was having a NGT inserted:

"*They were basically like you need to have a NGT and I, I remember very strongly kinda saying no please, like don't , I'll go to McDonalds, I'll eat anything, just please*

*don't give me the tube, but it was kinda, I was deemed incapable of making that decision at that time."*

In this passage Abby is focused on sharing how she tried to bargain with who "they" are, it was unclear during the interview if "they" referred to the hospital staff or parents. Abby presents herself as pleading and directly saying no to receiving the NGT. Of the seven participants interviewed, Abby is the only participant who directly stated they did not want the NGT.

As Abby spoke of her experience, she engages in taking a self-immersive position where she shares her experience and takes an active part. However, as commonly seen with self-immersive practices, she then takes a further step back engaging in self-reflexive practices (Ayduk & Kross, 2010). This creates a dialogue where Abby shifts between her experience as a child and how she managed the insertion experience then while also commenting on the experience as an adult. This is seen where she discusses being seen as incapable of making a decision over her own medical care. As Abby discusses the idea of capacity to make health decisions, it brings in a wider discourse surrounding both cognitive functioning and AN where those with AN at the time of receiving NGTs are often considered to be incapable of making health care decisions for themselves (Hoing & Bentovim, 1996), while also acknowledging a wider discourse around children's rights and abilities to consent to treatment. Therefore, Abby is touching on two sets of policies and legalities that impacted her care and framed her understanding and experience of nasogastric insertion.

As Abby talked about her experience of waking up and seeing herself with a NGT she states:

*"I had very odd images of what this //pause// mythical tube would look like, I didn't understand what it was um and even after having it, cause, I, I, the first place I got inpatient treatment was the medical ward, and I remember being in the bathroom and I was in, I was looking in the mirror and I yawned and I kinda saw the tube go down my throat and I freaked out"*

Abby reflects her confusion around having received a NGT. While she uses language such as "mythical tube", it is important to place the language she is using to describe her experience as deriving from when she was a child. Adding to this experience also reflects the lack of consent Abby provided in the procedure along with the lack of information she was given towards what to expect. This lack of information and consent given by Abby reflects a similar experience as the children participants in Neiderman et al.'s (2001) study where 71 percent reported they had not consented to the procedure.

While, Abby initially started off her account with an even flow and tone to her narrative, as she discusses the experience of waking up with a NGT the way she engages with her own narrative changes, with stuttering, repeating words and her use of pauses and silences becoming more prominent. As she proceeds through her account she initially utilises what is known as a cognitive function, where pauses and hesitations are reflecting cognitive processing (Matei, 2013). However, as Abby progresses through this experience of realisation about the NGT and continues her narrative, she shifts to affective function which is where silence is used as a means of emotional management. This is typically used as an individual gets closer to the discussion of a traumatic event (Matei, 2013). This, for Abby, is what proceeds the insertion and realisation of how the NGT functions within her.

Though the participants interviewed were from different countries and treatment centres along with being different ages, the process of having a nasogastric tube inserted was similar amongst them. The majority of participants were not under mental health legislation at the time of insertion, despite this they were not asked, nor did they give consent to have a nasogastric tube inserted. Following this, the procedure was not explained to them and was rather just done to them. In contrast participants who had the procedure explained in detail to them experienced a more positive insertion process and expressed less pain while reflecting from a self-immersive perspective.

**Am I sick enough?**

*"Someone on IG who posted a photo they had drawn, it was like a podium with first, second, third like at the top of the podium she had drawn a girl with a feeding tube, then the second podium there was a girl who looked underweight and she had no tube, and the third podium had a girl crying and I would say she had a healthy weight, and I would say that is how it's viewed, like you go not treatment and you don't get tubed, you weren't sick enough"*

- *Susan Lewis*

The medical community relies on a low BMI and physical complications to deem one sick enough to receive inpatient treatment, with only the sickest of individuals receiving NGTs. The NGT acts as an intersection for the symbols of illness and of the validation of sickness. This idea of sickness is often played out on social media and in interactions between patients and staff, leading to feelings of shame. Further contributing to these feelings of shame is the influence of the 'pro-ana' discourse on social media, where the NGT is often romanticised and symbolises 'being sick enough'.

The narrative point of ‘am I sick enough’ was present in a majority of the participants’ narratives after they had received a NGT. It is important to note why this point was not present in three of the seven participants’ narratives and why they were not included in this section. At the time of diagnosis and treatment both Abby and Neela were under the age of 12 and neither of them knew much about AN beforehand. Their decline in health was over the space of less than a month and due to the related complications with being younger and having AN, treatment centres are a lot more proactive in admissions (Starship, 2019). For Elizabeth, she was initially admitted into a mental health unit for a different reason and it was within there she stopped eating. She framed her reason of resisting food in the mental health unit as a way of harming herself since all other means had been removed. Therefore, there was not the same struggle to access treatment that the remaining four participants experienced as she was already in a mental health unit.

The remaining four participants were all over the age of 16, had experienced delays to treatment and had been told at one point or another they were not ‘sick enough’ to receive treatment. They also had the influence of either the eating disorder communities, pro-anorexia or had pre-existing ideas of what AN was before having their own diagnosis. Therefore, this also influenced how they had constructed AN.

The narrative point of ‘am I sick enough’ explores how the nasogastric acted as symbol of illness for both participants and also to those around them. The visible symbol of sickness was something that was at times both welcomed and at times ignored by participants.

Lucy reflects on her thoughts around getting a NGT:

*“I just kept thinking in my head, I’m so fat, I’m nowhere near sick enough for them to do it to me, there are so many more sicker people, they aren’t going to do it to me, there*

*was this really ugly ill part of me that told me if I get one, I'll be a proper anorexic, I'll look so cool, which is really disgusting and I'm ashamed that I thought thinks like this. It's not me that thinks like that but the unwell part of me"*

Lucy's initial dialogue reflects the typically psychological discourse, where those with AN are pathologized through section C of the DSM-5 criteria for AN that states "disturbed by one's body weight or shape, self-worth influenced by body weight or shape, or persistent lack of recognition of seriousness of low bodyweight." (American Psychiatric Association, 2013). Lucy then transitions to positioning herself from being nowhere near sick enough to acknowledging there are people who are sicker than her. This indicates that to some degree Lucy does realise and acknowledge that she is sick. Lucy is starting to grabble with this idea of being sick. As Lucy explores her thoughts around needing a NGT, she is oscillating between being self-immersive which allows her to speak of her thoughts at the time and then engaging in self-reflection as she comments on how now after a certain amount of time, she separates her thoughts now from her thoughts then.

A further linguistic strategy Lucy engaged in, which is frequently used in treatment, is the separation of the 'true self or authentic self' from the 'anorexic self' (Williams et al., 2016). The 'true-self or authentic self' is the person without the mental illness, this is considered to be the true persons values and beliefs. The 'anorexic self' is a specific set of thoughts that are considered to come from the eating disorder; this includes thoughts such as 'I'm so fat', 'I'll be a proper anorexic' and so forth (Williams et al., 2016). This separation provides a contrast between thoughts that represent 'sickness' for Lucy with her self-reflection thoughts which is coming from how she has positioned her 'true or authentic self' as critiquing her 'anorexic self'.

Lucy reflects this idea of not being 'thin enough' or 'sick enough' continues later in her narrative as she says:

*"I didn't think it would come to being tube fed, I always thought I wouldn't get thin enough, I wouldn't get sick enough."*

As Lucy repeats the idea of not thinking she will get to the point of being 'sick enough' it is reflecting a greater medical discourse deriving from professionals as well as specific online communities that communicate specific ideas of what being 'sick enough' means. From a professional perspective, those seeking treatment for AN often report having been told that they are not 'sick enough' (Ramjan & Fogarty, 2019; Treasure et al., 2011). Being told this by a person who is in the place of legitimising knowledge (Foucault, 1977) and therefore seen as being in a place of power in defining whose body is constructed as being sick, creates this paradox where the individual is being 'treated' as if they are not sick and therefore once they do get help the individual has been subjected to a iatrogenic environment in order to get the help they need, where they have gone from being treated and told they were not 'sick enough' to access treatment (Ramjan & Fogarty, 2019; Treasure et al., 2011) to suddenly being 'sick enough'. Being told this by a person who is in the place of legitimising knowledge and holding power (Foucault, 1977) constructs their body as sick or not sick. Therefore, this creates this paradox, where the individual is being 'treated' as if they are not sick and once they do get help the individual has been subjected to an iatrogenic environment. Where suddenly, the same person is now telling them they are 'sick enough'.

Outside of this medical discourse Lucy is navigating she is also navigating society's influence of what it means to be 'sick enough' with AN. For Lucy she has engaged in online recovery communities as well as pro-anorexia communities. These communities

both frequently show the NGT, almost in a place of 'honour' and romanticise the NGT. Within this setting the idea of sickness is reflected with the NGT acting as a tangible marker.

Finally, Lucy concludes with a reflection further constructing her identity as being in recovery and how her views about the NGT have changed as she is now healthy:

*"Prior to getting the tube I saw the tube as being glamorous, being amazing and like making you special and making you like a really good anorexic. When I got the tube, I realised it's not glamourous at all. Like, uh, like websites and pictures I use to look at of anorexia made the tube look very romantic"*

Lucy concludes her experience of being 'sick enough' engaging in self-reflection to bring us back to present day and present what Labov ( as cited in Riseesman, 2008) terms as coda.

In contrast to Lucy, Susan reflects on having had a NGT at one facility, having it removed and then being transferred to a second facility where the NGT was re-inserted. Consequently, she explores how it was to receive a NGT when she deemed herself as being a higher weight then other individuals in her treatment facility. As a result Susan struggled with this idea of being 'sick enough' through having the marker of a NGT, while feeling as if she no longer meets the standard idea of 'sick enough'. This struggle was magnified by the comments of other individuals and staff in the treatment facility.

Susan reflects a nurse saying to her:

"*Then this night the nurse came in and she came to put my feed up and she was like you're a healthy weight now, [removed for clarity], I don't think you need this anymore you should be able to eat".*

She then reflects on a similar sentiment made by a fellow individual at the treatment facility:

"*I don't understand why you do have a tube - you don't need it".*

Both the comment made by the staff and the other individual within the facility are demonstrating the wider discourse around what it means to exist in a woman's body in society. Despite Susan being in treatment for AN and having gained weight, both the nurse and fellow individual in treatment, have deemed that her body is now 'healthy' and no longer needs this intervention or marker for 'sickness'. Though they are not necessarily stating that Susan needs to lose weight, they are suggesting that her body is now at a position of health; this is regardless of Susan's own self-confession that she is still underweight at this point. These sentiments speak of the wider discourse around how women's bodies are now expected in society to be not only docile (Foucault, 1977), but they are also required to further engage in oppressive practices that further construct a docile body, so that the body remains at a point of being underweight where it can pass for 'health' without being healthy (Foucault, 1977).

As Susan's account continues, she speaks of another later experience of needing to be admitted into hospital due to medical complications relating to AN. However, at this time she was at a BMI that is perceived as healthy. This time Susan did not receive a NGT:

*"I was a healthy weight, so I didn't have one placed, which was actually quite fine with me, as I didn't need to gain weight. I was made to feel like you're not sick because you don't have a tube"*

Here Susan has taken on the biomedical discourse of AN, where despite the medical difficulties she is experiencing which are indicating her body is not okay, she assumed the position that her body did not need to gain weight and therefore, the use of the NGT

was unnecessary. Susan is defining her body as being docile and subjected (Foucault, 1977) and not needing to be intervened upon. She is also engaging in the discourse around how a female body should look and perform in society as she frames her body as healthy.

At the same time, Susan is trying to navigate having her body identified as being 'mismanaged' (Frank, 1995) due to the hospital setting and needing medical intervention. Therefore, as she says "I was made to feel like I was not sick", she also had positioned herself as being sick, otherwise she would have agreed with the position those around her were taking. This is all tied together with the symbolic meaning of the NGT. In Susan's circumstance the tube did not act as an external validator of sickness as she experienced those around her telling her she is not sick or the NGT was not needed, the NGT allowed for her to see herself as being sick, when she did not have a NGT she struggled with recognising that her body was experiencing medical complications related to starvation. Susan reflects on returning to the hospital with this want to be thinner so that she can be viewed as sicker than last time:

*"You kinda get into this whole I have to come back sicker and yes, I need to be tubed, because yes I need to show them how sick I am, because you get treated like that by professional"*

This behaviour is often characterised by professionals within the eating disorder field as being manipulative tubed so she can "show them how sick" she is was a result of how she was treated by professionals. Due to Susan's previous experiences this could be viewed as a passive resistance to how staff perceive her, because she ultimately is engaging in a common pathologized psychological discourse as a way to respond to how professionals have treated her. She therefore takes the position of being sicker in an attempt to get her illness validated by those within a position of power, whom in society are placed in a

position of legitimising who is seen as 'sick enough'. This idea of 'sick enough' therefore for Susan is both a resistance to, and succumbing to, the same discourse.

Throughout the interview, Susan often engaged in a pre-narrative (Riesman, 2008) as she tried to identify how the NGT or the lack of NGT positioned her as either being 'sick enough' or 'not sick enough'. Susan came to the conclusion that she would still, to this day, prefer to have a Percutaneous endoscopic gastrostomy (PEG) tube (Appendix A) and that this would allow her to confirm this idea that she is 'sick enough' without everyone else having the ability to comment:

*"For me, it was more in my head, okay I am sick enough, need this, but I don't want everyone to see it."*

This is an interesting change in dialect as Susan spent her time talking from an external perspective that illustrated wider societal discourses on anorexia and what constitutes as sickness, whereas as the PEG is hidden away it reflects a need for an internal validator of sickness.

Kerry also presented a similar inner argument as previous participants around this idea of being 'sick enough'. Kerry critiques how the biomedical discourse that is adapted by both health professionals and society around AN has positioned the idea of being 'sick enough' in a very specific way:

*"I think the idea of, a NGT, not the idea but like having it, which I know is lifesaving, it also reinforced the idea you have to be really skinny to have an eating disorder and that's a much wider problem than just a tube, but I think it's a little bit relevant. I think it's another sign that skinny people are really sick and here's physical proof on their face or whatever to prove that"*

Kerry critiques the dominant biomedical discourse on AN which positions those with AN as being underweight and skinny, rather than the symptoms being a reflection of a representation of a wider issue in society. In providing her critique of the NGT and the idea of being sick enough she makes room for narratives of those who do not fit that criteria, by recognising that there is a much wider issue in how we conceptualise what sickness means for AN outside of the NGT and low body weight.

Kerry's critique provided an interesting perspective over having a NGT where those in the position of power, which in this circumstance is medical professionals, hold a lot of weight in determining who is 'sick enough' and who can access treatment. There is a certain amount of power given to those who receive a tube for having AN and that this power is predominantly played out in the society and eating disorder communities. This power starts to draw on the discourse shared by Lucy which is the idea of "being a proper anorexic".

Kerry continues to share and discuss how though social media specifically, pro-recovery communities on Instagram, were not prominent when she had AN, she recounted an event where she took a photo of herself, so she could remember that there was a point where she was 'this sick':

*"I do remember, my// pause// hmm, I don't actually, think it was a pride thing in the sick sense, but I took a picture of myself with it, to remember that I actually had it, I was so distressed and in general and I wanted to have a, physical reminder showing myself that I had it and I was so sick, and I took a picture but my Mum deleted it. She didn't want any proof I had it".*

As Kerry discusses this experience she starts by distancing herself from those who have had AN and NGT in the last five years since the emergence of Instagram communities.

For Kerry it was important to distinguish herself and her act from how NGTs are shown in communities today. She further supports her act by reflecting that it was not an act of pride but rather to remember that she was sick. However, she concludes that her mum deleted the picture. This is an interesting series of events, as Kerry is the only participant who discusses her mum at any stage of the interview and with that, as Kerry is trying to navigate the internal battle around what it means to be sick with AN, her 'mismanaged' body because she has received a NGT, she also has her mum who deleted this picture.

While Kerry mentions this idea of being 'sick enough' and wanting that reminder of being sick, she separates herself from those who perceive the NGT or AN as being something to be proud of. In doing so she is rejecting the narrative of 'pro-ana' where the NGT is often viewed as something that one should aim for. Furthering this, Kerry spends her time reflecting on the idea of being sick through the separation of herself and her experience from modern day AN where social media has had an influence. In doing so she is seemingly situating her experience within a specific time and space prior to social media's influence. This does suggests the impact of social media has created a different idea of what it means to be 'sick enough'.

In contrast to the three previous participants experiences with NGTs, Carol was the only participant who received her NGT part way through her admission and also was part of the decision made in collaboration with her psychiatrist. As Carol recalls she was at a higher weight in contrast to the other individuals with NGTs and therefore she engages in a similar pattern of speech as Susan:

"*I guess there was some shame, I wasn't weight restored, but I was already up, like //pause// quiet a lot, I think there was a shame around me not being sick enough visibly or thin enough to warrant that marker … of being sick*"

While Susan drew on external factors to discuss the experience of receiving a NGT at a BMI higher than that of admission weight while still being underweight, Carol drew on instead her internal thought process and emotions, specifically reflecting on this idea of shame. Fessler (2004) suggests shame functions as a way of regulating social systems and hierarchies and can be responsible for social rejection as it contributes to maintaining societal norms. Within the context of Carol's experience, the use of the word "shame" is potent as it is implicitly indicative of the wider societal discourse around what it means to be 'sick enough' as someone with AN. While she notes that she was still underweight, she believes that the body weight she was at the time of her receiving her NGT goes against societal norms of what someone who is sick with anorexia may look like. Again, this idea of what someone with AN looks like draws back to the biomedical discourse which is dictated and legitimised by those in the medical field (Foucault, 1977).

Carol continues to discuss how she makes sense of her experience and navigates this idea of viewing herself as sick enough:

"*I kinda had this thing, where iiii, even though I needed medical stabilisation you know, that I had never been sick enough, I had never had this marker of being so unwell that I couldn't eat enough that would warrant a NGT insertion and so I think after that, like that's not what they were trying to achieve, it was almost like I had ticked off the box and could get better, It's not rational, but I guess eating disorders aren't rational yea."*

While at the start of her extract Carol, brings about the idea that despite needing medical stabilisation, which signifies that she was sick as her body physically was not coping with the realities of starvation, it was not until she had received a NGT that she felt as if she was unwell enough to get better. Expanding on this idea, it seems to be reflective of society's idea of what AN is. This is the picture of the girl who is unable to eat anything,

and that being sick with AN is not about the cognitive processes that drive the behaviour nor the medical effects of starvation, but instead this marker which tells of one's sickness. (Frank, 1995)

As Carol talks about her experience with AN, she is trying to make sense of what it meant for her to have a NGT when she did not meet her pre-conceived idea of what it meant to be 'sick'. This has created a sense of cognitive dissonance for Carol as she tries to make sense of what it means for her to have experienced this symbolism of sickness when she herself did not see herself as being sick.

Adding to this as Carol discusses what it meant for her to have a NGT and how this positioned and changed her perspective of her AN:

*"It was strong enough, that I, //pause// that I went through that process. That It was loud enough to mean, that I restricted enough, or fell back enough that I fell back into old behaviours that warranted tube feedings" ....*

*"Of having this very visible marker of what was going on, the sickness"*

Carol repeats this idea of having the physical marker of sickness. This repetition is further indicating how Carol is trying to make sense and engage in meaning making of her experience of being sick enough. These feelings are still prominent for Carol who, unlike the previous participants, was the only one who worked collaboratively with her psychiatrist. Despite his support and the collaborative nature, Carol still struggled to position herself as sick and still carried the effect of previous experiences where her experience of distress was ignored, and she was met with; not being 'sick enough'.

Finally, Carol summarises her experience with the internal battle that comes with accepting the NGT and this idea of being sick enough:

*"I think it does reward the anorexia in a way like, somehow I had achieved something, um //pause// but I guess the flip side of that, is, isss, failure at having managed the anorexia well enough to be in that situation. Or not having managed it well enough that is, um like, relief and uncertainty as to what was going to happen".*

*"It's coming from the eating disorder more from me, that I never, I was never that bad, because I was too compliant, to ready to try and follow the meal plan as best I could, I guess I get caught up, in a lot of comparisons as well. I don't know. Yea"*

Within these passages Carol reflects on the difficulty associated with accepting the NGT and how this created an internal battle. This is a battle where accepting treatment and the NGT without resistance and working collaboratively with her treatment team could be viewed as not being 'sick enough' or could be seen as attention seeking. During this, she worries that this is viewed as her compliance meant that despite her having what she refers to this marker means that she still was never bad and she was willing to try. This willingness to try and get better goes against the common discourse around AN, which reflects the idea that those with AN are treatment resistant (Strober, 2004). Adding to this idea, the acceptance of the NGT and her compliance resulted her in feeling as if she had been unable to manage her AN to end up in a situation that requires a NGT. This idea of failing to manage her AN is not a reflection on managing recovery, but rather managing to keep herself in a place of sickness that does not require medical intervention, therefore prolonging the period of anorexia and maintaining the sickness.

Carol's experience with NGT reflects the inner battle that can exist within an individual when receiving a NGT. This inner battle is one that is often not expressed or acknowledged within a treatment setting. The language Carol uses throughout, in conjunction with the pauses, stutters, and sentences that at times are repetitive or back

tracking, illustrate the difficult feelings, vulnerability and emotions associated with having experienced these thoughts and reflecting these to someone. This battle of wanting her experience of illness validated, which in the case of AN is signified through the NGT, happens concurrently with the battle from the externalised anorexia, where the individual has fears around being seen as too compliant and what this means for the validation the NGT was meant to bring.

This idea of being 'sick enough' often is thought of or perceived as being a manipulative characteristic amongst professionals who work with AN, to those who have been placed in the position of trying to navigate the idea of being 'sick enough' it illustrated a greater societal discourse, one where the appearance of AN is pre-set through both psychological and biomedical discourse. Within this those who have AN are often declined treatment as they are told they are not 'sick enough' for the level of care, and then once they are in that level of care, those with AN still conceptualise themselves as not being 'sick enough'. The use of social media, Instagram recovery accounts, 'pro-ana' communities, news articles and movies further influence society's idea that AN is something that is associated with extreme emaciation and NGTs and therefore if it does not meet this criteria, the individual therefore is not viewed as sick. Furthering this, staff and hospital peers further perpetuate the idea. Finally, as the participants themselves are part of society where these ideas are prominent, they too are faced with the idea of what a 'sick' anorexic looks like and engage, critique and resist such discourses to make sense of their own experience. This has appeared to be an incredibly complex cognitive battle that the individual engages with as they attempt to make sense with the ontological reality of the NGT used as a mechanism to make sense of their constructed AN.

## Types of nasogastric feeds

As the main function of a NGT in eating disorder treatment is to deliver nutrients to the individual, a common narrative point discussed by participants is the different ways they received nutrients through the NGT, and how this influenced their treatment experience.

Participants described and defined three different methods of nasogastric feeding: continuous feeding, nocturnal feeding and bolus feeding. Participants described continuous feeding as receiving a slow rate of nutrients over a 24-hour period delivered by a pump. At times continuous feeding is used in combination with oral feeding. Nocturnal feeding was described by participants as eating food during the day and then, depending on how much food they consumed, they would receive a certain amount of nutrients over a 10-hour period at night delivered by a pump. Finally, participants described bolus feeding as the process of a nurse using a syringe to directly deliver the nutrients into the NGT. The type of feed received by participants depended primarily on the treatment facilitates policies as well as the individual's risk of refeeding (Appendix A).

Of all the participants, Susan received the greatest variety of feeding methods and found that the way she received her feed was highly dependent on the facility she was in. Susan reflects that one facility had what was termed the "NGT Protocol". Susan describes this as patients were expected to eat a specific amount of each meal and drink all of the supplement drinks given to them, then the amount of food they were expected to eat increased over a seven day period. By day seven patients were expected to eat everything given to them. If at any stage, they were unable to complete the specified amount they would receive a NGT. If a NGT was inserted, they would then be placed on nocturnal feeds dictated by how much they ate during the day.

Susan found that being placed on the NGT protocol created an internal battle with mixed feelings:

*"On one hand it felt they very much were treating you like a child, and they were punishing you. On the other hand, it was difficult as if I eat it all they are going to think something is wrong, so you can't win either way".*

Susan then discusses an overarching theme that appears throughout this thesis, the need for validation of being sick enough to require the NGT compared to being pathologized because of the NGT. This idea of being sick enough expands outside of an internal need or the inability to see oneself as sick, as commonly pathologized through the DSM criteria for AN (American Psychiatric Association, 2013), and rather is reflecting a fear of what happens if the individual is not sick enough. Susan wonders how the staff will perceive her regardless if she follows the protocol or does not. This internal battle felt by Susan, where she is either punished or pathologized leaves her in a place where she feels like no matter what she does, she is going to be the one to lose. Therefore Susan is alluding to how those in treatment may perceive staff as pathologizing them and the risk those in treatment face if they do engage, comply and do not resist treatment, as they are then more likely to be discharged and lose the help.

Though the nasogastric protocol for Susan created a double-bind she still had a preference of feeding. Susan preferred the nocturnal feeds and found it caused less distress in contrast to continuous feeds. Susan found that nocturnal feeds took away the feeling of continuously eating and allowed for breaks between meals and snacks. In addition, having the amount of feed dictated by what was eaten during was helpful for Susan. Susan said at times she just needed "time off from eating", and she was able to refuse her meals during the day and then received a higher rate of feed overnight. This did mean that

overnight she was on such a high rate of feed that she ended up receiving around 400ml of feed per hour over a 10 hour period. This did cause feelings of fullness and was difficult going into the next day suggesting a double-bind again and there is no time off from eating in reality. This created an illusion of control

In contrast to nocturnal feeds, Susan explained how she found continuous nasogastric feeding as difficult and distressing:

"*If you have someone who is claustrophobic and you put them in a box for 2-3 hours, and every week you make the box smaller as every week your calories go up, and you're terrified and they tell you, no, no , no we are trying to keep you safe, it's just your ED talking, it's like no shit, I know this, but it doesn't make the fear go away*".

Using a metaphor in patterns of speech allows the user, in this case Susan, to borrow linguistics from one cognitive domain and apply them to another in hopes that the listener is able to gain an understanding of the experience without the listener having experienced it themselves (Borbelly, 1998). Throughout Susan's interview the only place she utilises metaphors is in her discussion of continuous feeding; this is telling of how the experience has been for Susan. The use of metaphors here indicate how the experience is one in which she is unable to access language to tell her truth and therefore is relying on the categorisation of other linguistic properties to explore her experience.

Furthering the use of this metaphor, Susan has not only tried to demonstrate the distress to the listener of how continuous feeds were experienced, but the use of the example of claustrophobia is interesting in the context of her previous discussion around the physical feeling of fullness and the embodied experience of having a NGT; with continuous feeding she physically would not be able to get away from the feeling of fullness or having the NGT inside of her. She also includes the comments made by staff where she reflects

this idea that staff are trying to do it to keep you safe and rationalise it through the idea that her discomfort is associated with the idea of the ED voice talking, rather than the possibility that she could be feeling uncomfortable due to the increase in food. Susan follows this up by saying that thought the staff saying they are trying to keep her safe, it comes off as patronising illustrating that they do not understand the embodied experience of receiving nasogastric feed, rather than coming across as supportive.

Susan, further utilises a second metaphor to explain her distress associated with continuous feeds stating:

*"Imagine I put you in a room full of dogs and leave you there for 24-hours, they are coming at you, trying to jump at you, it's continuous fear. Instead of doing it over 12-hour periods"*

Again, this reflects Susan trying to convey the fear experienced with continuous feed and how this fear is prolonged and continuous. In contrast to Susan, Elizabeth experienced bolus and continuous feeds. Elizabeth was initially started on bolus feeding, however this resulted in Elizabeth developing refeeding syndrome[4] and she was then placed on a continuous feed for around two weeks.

Elizabeth explains that for her the bolus feeding was incredibly difficult and she preferred the continuous feeds, she recalls:

"*I can't handle you putting it down and them doing it really slowly as it would make me feel so so sick and so extremely full going from eating absolutely nothing to these high calories drinks*"

Elizabeth received bolus feeding where a nurse manually would push the feed every two hours with the feed taking one and half hours. This was extremely draining for Elizabeth

and she found she never really had a break between receiving a bolus feed and then having the next one delivered. Furthering this, it created feelings of being physically in pain.

As Elizabeth explores her experience with bolus feeding she starts by talking in past tense, reflecting that she is positioning herself from a self-immersive position (Ayduk & Kross., 2010). However as she proceeds, she switches her linguistic strategies and moves from a self-immersive position to talking as if she was experiencing it again, as she changes to using the word 'you', rather than nurse/staff or they. This change in linguistic strategy reflects how Elizabeth changes throughout this section of her narrative between reflecting on her own story, to as if she was back in her own story. This is a common response with trauma narratives (Ayduk & Kross., 2010).

While Elizabeth's experience of bolus feeding was distressing and physically painful for her, her experience with continuous feeding was a lot more tolerable as she was able to distract herself and do things to take her mind off what was occurring.

For Abby she received a mix of continuous feeding and bolus feeding. With Abby when they started her on continuous feeding they were worried about the possibility of her developing refeeding syndrome and as a consequence they placed her on a lower feed rate which resulted in her losing weight while in hospital. The decision was then made for Abby to change from continuous feeds to bolus feeds in order to bring some normality. With Abby's experience of bolus feeding, she muses on the idea that there was a lot of miscommunication at this time of her treatment and notes she believes this to be partly due to how young she was so staff maybe made the assumption she did not understand. She also explains that this time in treatment was confusing as it was often clear that staff did not specialise in eating disorders and so staff seemed just as confused as she was.

Abby reports that:

"*I struggled with the feeling of fullness afterwards, um and they would always try and give me the option to eat food um, or have the bolus, but I like, it wasn't very structured, so I wasn't sure at the start, what would happen if I ate half the meal, but then would freak out if they would give me the whole bolus"*

For Abby this lack of structure was experienced negatively and further reinforced her self-proclaimed obsessive compulsive tendencies which caused her to fixate on the differences between bolus feeding and oral eating and the lack of organisation around these. During some point of the stay, the use of bolus feeding became unsafe as a nurse negotiated with her and then told her she had the right to decline receiving bolus feeding. This ultimately resulted in Abby being placed under mental health legislation and being held three-to-four times a day by individuals as someone would push supplement through the tube.

Abby stated:

"*That went on for a month, and it was kinda like, three or four times a day, like I would be held down, that was like, by big men, or nurses or my family and then some // pause// um, somebody, I would be on the couch being restrained and somebody would have the tube".*

In conjunction with this Abby had a previous treatment trauma where a prominent eating disorder professional instructed her parents saying "you need to get that food down that girls mouth". The professional then instructed them to manually force-fed her. Abby reflects:

"*My parents were desperate, the actual feeding had caused quite significant harm to my cheeks that the next day it had been like, it looked like I had golf balls in my mouth,*

*cause it was so swollen, and my parents were both, uhhh, crying and I actually thought in that moment I was going to die".*

For Abby the act of bolus feeding was one that was both incredibly traumatic in nature, but also something that reignited previous trauma that was carried out under the guide of a previous eating disorder clinician. For Abby, this experience created a loss of safety, lack of trust, an experience of trauma and highlighted the lack of knowledge in her treatment.

In Discipline and Punish, Foucault states the "body now serves as an instrument or intermediary, if one intervenes upon it to imprison it, or to make it work, it is in order to deprive the individual of a liberty that is regarded both as a right and as property" (1977, p.11). The punishment of force feeding, Abby's body has become the centre for punishment. While it no longer serves in the same way that punishment historically did in the public sphere, it has instead moved into the private (Foucault, 1977). The punishment received is acting under the guise of providing a 'cure or correction' of behaviour. Having others intervening on her body acts a source of embodied imprisonment, where the body has been deprived of rights and becomes a property of the medical professionals.

The language in which Abby uses throughout her speech further reflect this idea of lack of ownership over her own body, as she describes the ED professional where is she is no longer referred to as a person, but rather is referenced as "that girl's"; in this instance she has been dehumanised. Furthering this, Abby speaks to the wider macro forces involved in her care, specifically those afforded to those who are within the position of power and have legitimised her treatment, while her and her parents have succumbed to it.

Finally, from a linguistic perspective, throughout this narrative Abby's speech reflects a trauma narrative as her sentences jump over the place, and she uses multiple pauses, elongating words and using sentence fillers .

*"Iii //pause// I can't remember how long I felt okay in the [unit] meaning not unsafe, but , //pause// part way through that admission, um, I //long pause//…."*

This type of speech was common throughout Abby's discussion of the bolus feeding. For Abby, while she did not comment a lot on continuous feeding, the bolus feeding was a prominent part of her experience and a part that holds a significant amount of trauma.

Susan , Elizabeth and Abby discussed the different types of nasogastric feeding in depth in their narrative, thus indicating this as an important part of their story, Lucy and Carol reflected that while they had experienced a mix of continuous and bolus feeding, this was a minor part of their narrative and for them it did not expand beyond a sentence stating the type of feeding they had received. Kerry differed in her reflection, and her focus was primarily on eating with the NGT in and the subsequent lack of appropriate food for eating when you have a NGT; this is discussed in further detail in the section living with the NGT. Finally, Neela, did not discuss the feeding type with her NGT but instead reflects on her resistance to the NGT when it came to feeding, which is discussed further in the narrative point titled resistance.

Though only three of the seven participants spent time discussing the different types of feeding methods in detail this is still an important point of the overall story. For those who have discussed the feeding method, these were points of trauma and distress for the individuals. Bolus feeding was viewed very unfavourably while continuous feeding was viewed in a slightly more favourable light. It was nocturnal feeding that was perceived as the least traumatic and distressing.

## Living with the NGT

Though only three of the seven participants spent time discussing the different types of feeding methods in detail this is still an important point of the overall story. For those who have discussed the feeding method, these were points of trauma and distress for the individuals. Bolus feeding was viewed very unfavourably while continuous feeding was viewed in a slightly more favourable light. It was nocturnal feeding that was perceived as the least traumatic and distressing.

### *Physical Discomfort*

The most common comment made by participants was centred on the physical sensations caused by the NGT primarily physical discomfort. The physical sensations ranged from having the feeling of the NGT in the back of their throat to the feeling of having the tube flushed[5] each day.

For Kerry and Lucy, they both reported similar experiences of discomfort associated with eating while having a NGT inserted.

Lucy reflects:

*"It was quite painful cause when you swallow the tube sort of digs into your throat. It felt weird, like you could feel the food getting stuck on the tube and it is uncomfortable. I was reluctant to eat with it in, but they thought if they took the tube out wouldn't eat, I think it was there as a backup, but it made it hard to eat."*

While Kerry reflects:

*"I knew I did have to eat and it was even more uncomfortable and I wasn't keen on eating anyway, and I was like okay I have to eat because, um, otherwise if eating is the end goal, I'm never going to get the thing out to eat more comfortably"*

Both Lucy and Kerry found that the NGT caused painful sensations while eating. These sensations were described as tugging on the tube as they ate, food getting stuck on the tube and feeling as if the NGT was digging into their throat. Along with the physical discomfort associated with eating, they found themselves in a position where they were aware that to have the NGT removed would mean eating, which would cause pain, and this was worsened by the fact they already did not want to eat.

Within both passages Lucy and Kerry provide a self-immersive account of their experience allowing for them to provide a more embodied experience of the sensations associated with the NGT (Ayduk & Kross, 2010).

Keeping the NGT in once the individual starts to eat full meals again as a way of assuring the individual will continue to eat is a common practice with NGTs (Starship, 2019). However, while it appears as if it is an assurance to continue with eating, the NGT becomes a symbolic form of the greater control in an eating disorder unit. This control functions in two form; firstly marking the body as sick, and secondly the sensations providing a physical reminder of their mismanaged body and sickness, and this 'others' the 'patient' (Frank, 1995). The NGT being left in further demonstrates the idea that mismanaged anorexic body gives rights to medical professionals in the treatment centre and that it is acceptable for the body to become the property of those who legitimise knowledge and functioning. Manipulating the body in the way of leaving the NGT in acts as a way of punishing and correcting the body to ensure it will continue to act in a docile manner (Foucault, 1975). NGT are deemed necessary when the patient is medically

unstable but when the individual is no longer at a place of medical instability, the body is still at a BMI which is not considered normative within society. By leaving the NGT in at this time, this is a way of ensuring that the body will reflect a normative, feminine body that is docile which in turn ensures that the body still is gaining weight and that the individual is left in the realm of patient rather than being an embodied individual.

Abby experienced similar sensations to Kerry and Lucy, however her feeling of the NGT expanded beyond eating and was a presence she felt all the time:

"I *was always very aware that there was something in my nose, in my throat, even, not eating, but also eating, swallowing, I would feel it move all the time.*

Abby likewise positions her narrative from a self-immersive position where she talks about the embodied experience of having the NGT for her. She frames the experience as a consistent feeling which travelled down from her nose to her throat. It creates an embodied reminder that they are unwell.

To return to Kerry's perspective, while she experienced the discomfort with eating, she also experienced the NGT as making her feel as if she could not breathe:

*"I think just the feeling of it in my throat, was just the most distressing um, part of it and , I could also feel it further down, but that wasn't the most, I really think because it felt like I couldn't breathe properly, I know that I could, I know it doesn't cut off your air ways but that's what it felt"*

While on a logical level, Kerry was able to identify that she knew she could breathe, this did not stop her from feeling suffocation, and the related distressed by Kerry provides a powerful metaphor for both the controlling nature of inpatient treatment (Bell, 2006) and the intrusive nature of the NGT. Kerry did not have the ability to communicate the distress and fear of her body as it has become the objectified medical body (Leder, 1984) and she

therefore adapted medical language to communicate the related distress through expressing she felt like she was suffocating or unable to breathe (Frank, 1995).

Elizabeth offers a contrasting experience of the NGT:

"*They said it would be more comfortable once the wire comes out from it, It wasn't more comfortable when the wire came out, but after a few days it definitely, it wasn't normal , but you know, you didn't really feel it"*

Of the participants, Elizabeth was the only participant that spoke about staff saying that the NGT would be more comfortable. However, as she speaks about it being more comfortable once the wire comes out, it suggests that this conversation took place during the insertion process, as after insertion the wire is removed. As Elizabeth continued, she describes that it took a few days for the sensation to decrease but acknowledges that it "wasn't normal" but also something she "didn't really feel". In this situation Elizabeth provides a contradiction of her experience; she explores this idea of how the feeling did not improve, recognises that it was not a normal feeling, then seeks reassurance by saying you know, and concluding with "you didn't feel it". The way in which Elizabeth speaks about her experience is from a disembodied perspective where she does not seem to be able to navigate the physical feelings associated with a NGT. While individuals may use similar linguistic strategies, like Kerry uses where she adapts the language of those in power to describe her experience, alternatively they may use metaphors which function as a way of describing an experience which might be too difficult to address directly (Rechseiner et al., 2019). Kerry instead is demonstrating that she is still in her pre-narrative stage and is engaging in cognitive processing (Matei, 2013) as she makes sense of her experience.

While these four participants explored the physical discomfort associated with having a NGT they made sense of their experience utilising a variety of different linguistic techniques. As research is yet to examine the physical sensations related to nasogastric feeding, this is something that should be examined further. Specifically, as oral intake in combination with nasogastric feeding are a common practice in inpatient units, looking into how to decrease the discomfort could be beneficial.

*Physical movement limitation*

While participants experienced a range of physical sensations with the insertion of a NGT, participants also experienced restriction to physical movement after the insertion of a NGT. This includes the limitation of having to call a nurse to go to the bathroom so the feed could be disconnected to being placed on bedrest. Both Abby and Kerry experienced different degrees of movement restriction after the insertion of the NGT.

Abby was placed on full time bed rest after the insertion, as she explains:

*"I wasn't allowed to move at all basically, I was wheelchaired to the toilet, to the shower, I wasn't allowed out even on the wheelchair"*

While Kerry experienced a restriction to movement in terms of being allowed to shower:

*"I wasn't really allowed showers for a couple of days"*

Limiting movement for those in inpatient units who have a diagnosis of AN is a reasonably common practice as it is a way of theoretically limiting the energy being exerted to limit weight loss through movement. Though this is common practice in inpatient treatment, Ibrahim et al (2019) found no evidence to support the practice of bed-rest for AN as there is no benefit or protective factor associated with such practice. In addition, Ibrahim et al (2019) identified a number of negative risk factors being associated

with bed rest (which is what Abby is referring to within her extract), specifically physical and psychological harm. Despite such research surrounding the use of bed rest, it is continued to be used within inpatient treatment.

Abby highlights with her experience how the use of bed rest consists of surveillance and routinisation (Foucault, 1975) and is part of a wider macrosystem of power that exists within the treatment practices of AN; the hospital acts a medicalised panopticon, and the patient is the prisoner (Bell, 2006). The individual therefore is placed under the medical gaze and movement is restricted under the guise of a medical intervention. However, bed rest in conjunction with the NGT is yet another way that the body is attempted to be made docile (Foucault, 1975).

The NGT can be used as a form of disciplinary power within the in-patient setting in the context of AN. The NGT has been used in similar manner throughout history in both asylums and with suffragettes (Miller, 2016).The reflections provided by participants illustrate how simple experiences such as having the NGT being left in as a safe guard, being attached to the NGT even when the NGT is not being used or the limitation of movement due to the NGT are all reflections of disciplinary power in action. The aim of this disciplinary power is not to inflict harm on the body, but rather it is a power that claims to be able to change people, masking their behaviour to be 'proper' for society. Through this symbolism of power, the individual reflects the power dynamic and how as a society we internalise it and use it as a way of changing our own action, therefore further regulating the disciplinary power and creating the social body (Goffman, 1961). This is seen in aspects of the participants reflection, where they talk about having the NGT as a motivator to eat, so that the physical discomfort is minimised.

While the physical aspects of living with a NGT represent a medicalised docile body, the emotional aspects of living with a NGT on a macro level reflects further how the body is being normalised through specific practices, while the emotional aspect reflects how these practices to normalisation are embodied.

*Emotions and the NGT*

Both Abby and Carol discussed their experience of their affective processing around having a NGT (Matei, 2013). A common theme for both was the idea of how the NGT 'othered' them (Rechsteiner et al., 2019), making their illness more visible and leaving them feeling isolated and alone.

Abby reflects how the NGT was a constant reminder:

"*I guess there was always that reminder that even at Christmas time it was me with the tube and my continuous feed with my family, so it wasn't like I could just blend in"*

While Carol laments:

*"It was just you, and the tube and feeding and lots of quiet….. It was a lot of emptiness as well, I guess. To think and ruminate, yea be alone".*

Both Abby and Carol engage with a sense of ownership of the NGT as they discuss how it was just them and their NGT. Though previous research on NGTs has not explored this idea, previous research on the lived experience of inpatient facilities has found a similar sentiment of isolation in treatment where participants position themselves as being alone with their eating disorder and it consequently becomes a protector (de la Rie et al, 2006).

Furthering this, while having AN is viewed as having a mismanaged body through Arthur Franks' theory, the intersection of the NGT speaks further to the illness on the body, reflecting this idea that she is living in a 'disciplined body'. Within Frank's (1997)

explanation of the disciplined body, the body is at the centre of loss of control where it has become dissociated by itself and is something to be treated. This regimented treatment is carried out with precision, in this process Abby and Carol adapt a monadic positioning of their bodies where they take the position that they are alone with their illness, rather than a dyadic positioning where there is recognition that their experience is not theirs alone.

## Resisting the NGT

Though participants discussed resistance during the insertion process, this form of resistance in terms of themes and narrative points have been reflected differently and hold a different meaning, to resistance behaviour that occurs during the treatment process. Resistance during the treatment process has been categorised as behaviour that includes modification or alteration to the NGT or nasogastric feeding and resistance is often viewed as being treatment resistant or pathologized as mitigating attempts for weight gain (Abbate-Daga et al, 2013). Within this study, when participants spoke of the act of resistance, these incidents were not connected as a way of mitigating weight gain and rather reflected an emotional state.

Susan speaks of her experience where she "Ripped" her NGT out of her,

"*…At some point you do, do when you're distressed, like I've ripped mine out and everything, you get distressed and you're like I've had enough this [sic] coming out and you rip it out, I've had enough , you know ?...*"

For Susan, she frames her act of removing the NGT in the context of feeling distressed, during this passage she does not associate the feeling of distress with food or weight gain, but rather is symbolic of her being fed up with treatment and all that comes with it. The

use of the word ripping, rather than removing, reflects the highly emotional state associated that Susan was in at the time of removal. The idea of ripping it out of oneself speaks of the internalised and embodied aspect of the NGT rather than a symbol of AN. The NGT is also illustrating the greater complexities that come from recovery and living with AN. The act of ripping it out becomes a way of dissociating oneself from AN and the confines of treatment and it represents having enough of everything associated with treatment.

Along with Susan ripping out her NGT, she also altered the NGT

" *So then I started to tamper with it, which is great, then I got caught, I got a bit adventurous one night, the panic would set in, I would think what have I don't to myself, I need to get this out, then you get it out, then if you take it out they have to put it back in."*

The language used by Susan here is particularly interesting, as she uses words such as "tamper" and "adventurous", while also utilising external demonstrations of internal talk "which is great", this creates an interesting dynamic within her sentence. The use of such words depicts an almost childlike behaviour where she can be viewed as being mischievous or naughty. Within this extract, Susan also talks with a sense of urgency around the tampering with the NGT, specifically as she talks about the panic setting in and the sense of self-blame associated with receiving a NGT. This further contributing to the urgency to change, remove or alter the NGT in hopes of making it more manageable. Finally, Susan reflects the consequence of altering or removing her NGT, which is either the reinsertion or having further restrictions placed around the nasogastric feeding pump as a way of deterring future tampering. As Susan discusses her experience with resisting

the NGT, she relates the experience back to her personality type and how difficult it was for her to actually do these things

*"I was one of those people who was like a teacher's pet, I liked rules, I liked structure, so it made it hard as I was like trying to fight against that"*.

This act of resistance therefore extends beyond the physical realities of the NGT, and resisting against the hospital stuff, but also reflects a resistance to the individuals values as she tries to negotiate the panic, feelings of distress, the level of surveillance that comes as a result of her interference with the NGT, and cognitive dissonance experienced by Susan for going against how she perceived herself. Consequently, this results in a complex situation that expands outside of eating and weight gain.

In comparison Lucy reflects on her experience, where though she did not remove her NGT, she did use a syringe to remove her stomach contents through the NGT

"*I use to get a syringe and try and syringe the feed out of my stomach with a tube, that sounds disgusting, you know the tube, it's in your stomach and they put the feed into the stomach and after they left I would take a syringe and I would try and syringe the feed out of my stomach"*

Because of this resistance Lucy was always placed on a one-to-one watch with a nurse watching her. While Lucy did not expand on or explain why she did this, she talked about how she learnt how to do it, which is by watching the nurses take aspirates after each feed. This direct act of resistance is unique in contrast to the other participants in the study, most participants resisted through either the removal of their NGT or fighting back with staff. Lucy instead used the same mechanism by which she was fed through the NGT as a way of then resisting it. This resistance was more subdued than the others and

seemed to reflect a strong opposition to those in authority, as she mirrored the behaviour of the nurses.

Abby and Neela experiences of resistance was incredibly traumatic and has had a long-lasting effect on their lives and development. Both Abby and Neela were under the age of 12 at the time they received their NGT and were placed under the mental health act. Abby and Neela would continuously remove their NGTs and then would also physically fight out against nasogastric feeds, this included hitting, kicking and biting nurses. Consequently, they were placed in seclusion rooms, restrained, held down, were covered in bruises and at times sedated. For Abby and Neela their acts of resistance were meet with further invasions upon their body and this was met with further resistance from them creating a cycle between them and the staff.

Initially when Neela entered treatment the first time, she felt that she complied with treatment, where the second time, she describes it as something switched and she's unsure as to why.

*"I feel like I turned into a monster, I don't really know why, what happened, I completely struggled against the NG tube, they started using, um hospital staff to begin with, I was like uh, physically assaulting a few of them, they were trying to restrain me, hold me down, take NG tubes, they started using orderlies, I think I was screaming. It was chaos"*

Neela uses a metaphor in exploring the idea of her switching and compares her actions to that of a monster, she is unsure what happened to her or why she suddenly would no longer comply with the NGT. The lashing out and physically assaulting nurses resulted in her being restrained. While the scene itself is chaos, the chaos experienced is a lot more multi-layered and reflective of the greater level of chaos in treatment for AN.

"*They were a lot more use to restraining people, it's in their practice, so they had lots of techniques and binds and holds and that sort of thing, there were a lot more, I would say uh, //pause// you know, it was um, it was very , yea it was probably, it was , yea, there is still a lot of trauma of the visual feelings of being held down"*

Neela reflects that the use of restraints in response to her resistance became a normative part of her treatment, not only that, but it was a normative part of the treatment facility. Within this extract as Neela talks about it, she not only names it directly as traumatic and reflects on how she still experiences visual feelings of being held down, 17-years later, but her pattern of speech here, also indicates the experience of trauma, while the use of words such as um , and yea, can in certain contexts be considered as speech fillers, within the context of repetitive "um", "yea", pauses and the starting and stopping of sentences are all indicative of trauma linguistics (Latorre Gentson, 2012).

Neela talks in a similar manner again, where she tries to explain about why she was hitting out at the nurses, however, is unable to remember this.

*"I was being, I did assault nurses, I remember, I don't remember, I don't remember the first time I started people at the hospital, I don't remember , it was just, uh, you know, I think I bit one of the nurses quite badly, I would hit out, obviously, I remember there was a nurses, I really liked her too, but I think I just got really, you know, completely chaos in my mind, I would just fight anyone in my mind who would try and force this on me".*

Within this quote, Neela, demonstrates again this idea of being unsure of why she was resisting, using the same words as before and describing the chaos that was in her mind. Furthering this, her speech also repeats similar trauma linguistics as before, where she is repeating phrases "I remember , I don't remember", sentence fillers such as "uh" and

sentences that start, stop and then restart at a different place are all indicative of trauma linguistics.

Abby had a similar experience to Neela and utilises similar linguistic strategies for sharing her experience. Abby distinguishes that in her experience there was a difference between receiving nasogastric feeding and force feeding. For Abby the force feeding was a consequence of her resisting the NGT.

*"So before that I had been fed through the tube, but this was the beginning of force feeding, so //pause// I , that went on for a month and it was kinda like, three or four times a day, like I would , I would be held down by big men or nurses or my family and then some //pause// um, somebody, I would be on the couch being restrained and somebody would have the tube"*

In speaking of her experience, Abby's pattern of speech, she utilises pauses, "um" and the start and sudden stopping of sentence ideas. This again reflects the repeated traumatic nature of her experience in being force fed.

Abby discusses how she experienced the NGT stating

*"I was never really , uhhh, given control or treated like a human, you know, the treatment in [removed] was very dehumanising, the tube played a big part in that, it was something, again, I didn't realise how invasive I found it, um // long pause// especially because I knew it was there against my will. It was saving my life in a way, because it was giving me food, it was all very jumbled and not explained. Far too much to kinda process in a person with an underdeveloped brain at that age".*

When placed in the context of her resistance to the NGT, she discusses the lack of control, dehumanisation, the invasiveness and how the NGT played a significant part in this. Similar to how Neela used the word chaos, Abby refers to the experience as being very

jumbled, both depict the lack of understanding and confusion both Abby and Neela were feeling during this process. This lack of understanding is a direct reflection on the lack of knowledge and consent given to those in treatment for AN, this is further felt by those who are minors.

"*I just felt like, because it was a symbol of unwellness, it was also a sign of , like, lack of autonomy, lack of control, lack of say, and yea, it just , the whole //pause// the tube was just one of the //pause// parts of treatment that really emphasised //pause// to me as a child, kinda, made me feel like, I wasn't even human"*

Abby reflects a similar sentiment again, that the NGT is reflecting to her the lack of autonomy, lack of control, lack of say and feeling less than human. More than that, the NGT reflected a sense of unwellness. Therefore, in rejecting and fighting against the NGT, it is an attempt to gain control and autonomy over herself while also acting as a way of rejecting her status as being unwell. Furthering this, the staff response to her resistance was almost animalistic in nature as force, restraints and sedation were used as a mechanism of control.

Though both Abby and Neela resisted the NGT using physical violence. /this resistance is overt and indicative of highly problematic processes with in-patient treatments especially for minors. Both Abby and Neela were children at the time this occurred. While Abby discussed how her brain was underdeveloped and unable to process what was occurring at the time, Neela described this event as her mind just being chaos. Both reflections speak of how cognitively, neither of them were able to process what was occurring and happening to them. Therefore, though biting and assaulting nurses and staff may be perceived as shocking or disobedient, or you might ask yourself 'how else could the nurses have contained them as patients?' , this act of resistance speaks of the high

level of distress they were in and the level of threat they assumed was on their bodies. Once they resisted the first time, it created an environment of fear or each subsequent feed creating a cycle that is difficult to break for staff and patients. Contributing to this was fear in relation to safety and an attempt to re-gain a sense of autonomy over themselves in the only way they knew how.

## Reflections

Though the previous sections have examined narrative points and the prominent themes that emerged through each of the narrative points, the point of this section is to conclude with each of the individual experiences with NGTs. Due to the narrative format and aligning with my aim to provide participants with a place to share their story, this section is written in such a way to conclude their experiences without my interpretation or interjection of theory.

Abby Lockhart: Was the youngest participant to have received her NGT, consequently, the most amount of time had passed between her experience and her re-telling of it. The experience with the NGT for Abby was traumatic

*" the whole experience, tube and everything else so traumatic, that I just kinda tried to , deal with everyday life and go through the motions of finishing school and going to uni, you know, moving on from the past, but as it does, m, it kinda crept up on me*".

For Abby she experienced a period of what she viewed as recovery and relapsed; the relapse resulted in her needing to be placed back within the eating disorder services. At this time, Abby experienced a retriggering of the experiences that occurred during her initial treatment. It was during this relapse she was able to start to process what had occurred during her childhood, she states

"*I think that whole experience, changed //pause// definitely changed the way //pause// I view myself, and the world and kinda my goal going forward is to reground myself in my body and feel safe again, you know. Cause I think the tube was very, it felt unsafe a lot of the time, even though it was meant for safety, which is very ironic*".

While Abby had a traumatic experience with a NGT, she acknowledged that in certain circumstances it is needed, and reflected that clinicians needed more training around working with eating disorders and introducing the tube with a greater focus on humanising and providing autonomy to those in treatment. Having later experienced this humanising and autonomy within a treatment setting, Abby reflected the idea that to her

"*You are not your eating disorder, it also gives hope, it gives you an incentive to want to get better and kinda reminds you that you have this voice telling you and controlling you, but you also have , you have power and you have autonomy*".

Carol Hathaway: Worked collaboratively with her treatment team and made an informed decision to receive a NGT. She contributes the collaborative nature to reducing what she recognised could have been a traumatic experience. While Carol had a collaborative experience, she found herself struggling with the perception that she might have been too compliant in treatment, too ready to try and follow her meal plan. This often showed through in feelings of guilt and thoughts of being underserving of the treatment. She concluded her experience by saying

"*I mean I found it mostly, difficult, but positive experience, but I'm aware that's often not the case, so I feel lucky*".

Elizabeth Corday: Elizabeth  she did not agree with the decision to receive a NGT. For her, at the time of having had the NGT, she did not see herself as having had AN and rather saw her behaviour as a form of self-punishment. It has only been in the last couple

of years she has been able to unpack and discuss this experience with therapist in order to process what happened with her treatment.

On the other side of her experience, she experienced the NGT as a safety net and something that was easy to rely on, once it was removed this made her question if she was still sick or if she was now healthy, especially as she was considered a healthy weight. When thinking about her experience with nasogastric feeding and recovery, Elizabeth reflects

"*I personally think recovery happens, not in a hospital, it happens the day you go home, you don't have any support around you, you have to make the decision to do everything, you get fed in hospital, you get your meal provided, I think your real recovery starts the day you go home, you have to do everything yourself and make you do it, there is no one keeping you accountable , so yea, although it helped me, it only helped me out of hospital. It was all me doing it out of hospital*"

Kerry Weaver: To this day Kerry considers her NGT as one of the most traumatic things she has been through. When her NGT was removed, she reflected how she experienced a sense of emotional relief. To this date she still disagrees with the decision and perceived this treatment as a reflection of the lack of emotional support offered by staff in conjunction with their lack of knowledge of eating disorder treatment. Furthering this, Kerry reflects on the impact NGTs had on her recovery, stating that the only thing it did towards recovery was make it so she never wanted to have a NGT again. She concluded her experience by saying

*"They just did not know anything about eating disorders, they didn't have a ward, they didn't feel like they needed to know, [removed for privacy], they didn't really care I think they just stuck it there and didn't disconnect it. It was literally unnecessary"*

Lucy Knight: Lucy was the youngest participant at the time of the interviews and had the least amount of time pass between her NGT and interview. Lucy agrees in hindsight with the decision to be fed via a NGT

" *I think within the days leading up to it, even the months leading up, I l kinda really lost the ability to eat normally, I think the tube was a really easy way for me to get the right nutrients at the right times at the amount I needed. It took the responsibility away from me".*

While Lucy initially states that she thinks the tube helped with recovery at the time as it took the responsibility away from herself, she also recognises that at the time of receiving the NGT she was not in a recovery mindset and so having the feeding tube and being in hospital did not equal recovery.

"*It took me a couple more years, more therapy, more growing up, more other things, it wasn't the tube that made me recover, do you know what I mean. I suppose it was part of it, but it wasn't the main motivation".*

Neela Rasgotra: Neela was the second youngest participant to receive a NGT, consequently, it had been close to twenty years since she had a NGT. Her experience of having a NGT was also experienced as traumatic. She still experiences a lot of anxiety because of her experience, while she has spoken to a therapist about it to process the experience, she is still left with a lot of questions, emotions and feelings around her experience.

Neela experienced fear following her experience and the only reason she ate was to avoid going through such an experience again. Neela reflects

*" I still think quite a lot about what treatments could have helped me more, how could this have been a less traumatic and drawn out experience, because even after the*

*hospital admissions, I was under community mental health for a while, it was a large stint of my life. It feels like I missed on a lot of school, a lot of life, I sometimes wonder how this could have been better for me".*

This experience of having a NGT to date is something that still impacts and has shaped who Neela is and how she exists within the world:

"*It was a very traumatic time of my life, I mean there was a lot of awful things going on, I think it totally shaped who I am today and although I have a lot of sadness around critical point in my life that I missed because I was in hospital, like living with my family, I would say that I really to this day want to make the most out of the events which happened in my life".*

Susan Lewis: Susan Lewis had received the most amount of NGTs out of the participants interviewed, as a result her experiences are a collective reflection. Susan's first experience in trying to get help for her eating disorder has left a mark, she explains

" *I got diagnosed with AN in [year], the psychiatrist in [unit] and I quote sat there and said to me , you don't deserve help because you're not severely underweight, I went okay so my very limited knowledge of eating disorder at that point, was okay, I need to get really really sick, and have a tube, and if I had a tube, then I would get better. That's what you think don't you, you go into hospital they do their medical procedures, you come out and you're better".*

Susan found that the use of the NGT made her feel more reliant on her eating disorder

"*I think in some ways it made me more reliant on my eating disorder, because it was the ultimate way of not needing anything. I am quite aware that you need not say food, calories to survive. Like I'm not stupid. I know you need it. But having the tube was a way of getting all that while still be able to, physically not intake anything."*

To this day Susan found the NGT a safety net, and while she does not want an NGT due to the physical marker that can be seen by all, she does wish that she could have a PEG tube as this would allow her to get nutrients without having to eat.

# Chapter Five

# Conclusion

With my thesis I have found I constantly am caught between the theoretical and then the ontological reality of AN. AN is serious, more so the impact of starvation and malnutrition have very real long-term complications and death is a possibility. Therefore, as I have analysed my research, I have often been aware that without the intervention of NGTs, there are real irreversible consequences. In saying this, like AN, NGTs are complex. Yes, they are a medical intervention, but they are also complex and filled with paradoxes for those who are receiving them. While it is typically assumed that the rejection or resistance to nasogastric feeding is an attempt to mitigate weight gain, the complexity extends outside this symptomology. The NGT itself is not the issue, it is the way in which they are used and the structures and policies that occur within the treatment for AN that create these complexities.

The use of NGTs in mental health settings differs greatly from those in medical settings, often reflecting their histories of having been part of the inhumane treatment in asylums. Despite the belief that psychiatric institutionalization is no longer (Goffman, 1961), the anorexic body has been constructed in a way that it has become highly stigmatised, with inpatient treatment playing a part in this.

The anorexic body becoming a symbol of the mismanaged body (Frank, 1995) messages in which the female and gendered body receive in society, where the body is expected to be presented in a way and engage in certain dietary disciplines to be docile (Foucault, 1977). However, the anorexic body has become one that no longer is engaging in dietary practices in a specific way and has become uncontrollable through self-starvation.

Therefore, in order to correct the mismanaged body (Frank, 1995) and recreates the docile nature it enters treatment.

In order to the correct the mismanaged body (Frank, 1995) the body is infringed upon through the use of the NGT. Though the NGT functions as a way of keeping the individual alive and preserving the reality of having a human body, on the macrolevel the NGT is embodying and demonstrating a much more complex set of sociocultural powers, consequently, it is those with receiving the NGT who are left to navigate these. These internal battles are usually not discussed or acknowledged within the treatment setting and instead pathologized as a form of treatment resistant.

Those receiving a NGT are often either under mental health legislation, threats of mental health legislation or have been told they do not have the cognitive competency to make treatment decisions. Consequently, the insertion process often is a portrayal of the wider power dynamics that exist within a mental health facility.

Though a NGT might have been needed, it is the lack of explanation of what would occur in this invasive medical procedure that often left participants experiencing the insertion process as traumatic. Participants frequently drew on linguistic strategies that are common for individuals expressing trauma. There was no regard for the individual's wellbeing and therefore while the individual may not have consented to the procedure, there was also no opportunity for the procedure to be explained to participants. This often resulted in the participants having to engage in self-monitoring strategies (Foucault, 1977) out of fear that if they react, they would be placed under mental health legislation or they are placed under restraint. This action of resistant to the NGT has been pathologized in

the macrosystem. Therefore, in providing a more humane treatment, the results of this study would recommend providing the individual with information on how the procedure will take place and explaining where the NGT goes.

While the insertion of the NGT was experienced as traumatic, the greater complexity for participants occurred after the insertion as they found themselves navigating their own feelings firstly around what it means to be sick enough, this is particularly prominent for those who had difficulty initially accessing treatment and experienced the route to inpatient treatment acting as an iatrogenic environment, where to access help they need to become sicker and meet this idea of being sick enough.

The idea of being sick enough has been legitimised through the medical discourse which society and online eating disorder communities have since adapted. Therefore, when participants do receive a NGT, although they had envisioned this as someone who is sick enough, when it came to the self-reflection, they struggled with perceiving themselves in this way. This argument then extended to feeling as if by engaging and not resisting treatment they will be perceived by staff as not being sick or that something is wrong with them, where on the other hand they were aware that by engaging in acts of resistance they would be met with force.

Consequently, regardless of the actions they take they feel like they are at a loss. This internal experience felt by participants is not acknowledge or discussed in treatment settings, participants continuously described this double bind throughout their treatment experience.

Participants who did not resist experienced feelings that they were not sick enough, despite having medical complications and a NGT, while those who did resist have been

left with long withstanding trauma; This was particularly prominent for those who experienced treatment during their late childhood and early adolescence. Therefore, as discussed by Goffman (1961) while society believes mental health units have gone through a process of deinstitutionalization, in the context of treatment for AN, psychiatric institutionalization is still prominent within this treatment setting leaving those in treatment feeling as if they are engaged in a series of "crazy making" where the very treatment setting due to the pathologizing by health professionals have legitimised what is constituted as being sick , participants react by taking up this position. Furthering this AN then takes up the position of being a competitive illness, without really examining why. The NGT, therefore, is the ultimate symboliser of being 'sick enough', and even then, it is still riddled with the power discourse and feelings of not being sick enough.

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# Appendix A Glossary

Abbreviations:

**AN:** Anorexia nervosa

**BMI:** Body mass index

**NGT:** Nasogastric tube

**PEG:** Percutaneous endoscopic gastrostomy

Glossary

**Bolus Feeding:** A syringe is used to send formula through the feeding tube. A bolus refers to one meal (Memorial Sloan Kettering Cancer Centre, 2020)

**Continuous Feeding:** The delivery of typically 1000ml or 1500ml given over a number of hours using a pump that controls the rate and flow of the feed (Nutricia Advanced Medical Nutrition, 2019).

**Cognitive Competence:** A psychological construct that is inferred from an individual's behaviour. It is often used in determining if those with mental illness have the legal capacity to make decisions about their treatment (Wang, 1990).

**Fortisip:** A high calorie nutritional supplement, designed for dietary management for those with malnutrition, patients with high energy and protein requirements and low residue diet (Nutricia Advanced Medical Nutrition, n.d.).

**Nocturnal Feeding :** A continuous feed delivered overnight.

**Nasogastric Tube:** A flexible rubber or plastic tube that is passed through the nose, down the oesophagus and into the stomach. It is used to deliver nutrients to those who are unable to consume enough calories orally (Tresca, 2020).

**Refeeding Syndrome:** A potentially fatal reaction to shifts in fluids and electrolytes. It may occur in patients who are malnourished and are receiving artificial feeding (including nasogastric tubes) (Mehanna, 2008).

# Appendix B Changes in the DSM over time

| DSM-III (1980) | DSM-IV (1994) | DSM-5 (2013) |
|---|---|---|
| Diagnostic Category: Disorders of Infancy, Childhood, or Adolescence | Diagnostic Category: Eating Disorders | Disorder Class: Feeding and Eating Disorders |
| Intense fear of becoming obese, which does not diminish as weight loss progress | Refusal to maintain body weight at or above minimally normal weight for height/age (less than 85 percentile) | Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory and physically health. |
| Disturbance of body image, e.g. claiming to "feel fat" even when emaciated | Intense fear of gaining weight or becoming obese, even though underweight | B) Intense fear of gaining weight or becoming fat or persistent behavior that interferes with weight gain |
| Weight loss of at least 25% of original body weight or, if under 18 weight loss from original body weight plus projected weight gain expected from growth charts may be combined to make the 25% | Disturbed by one's body weight or shape, self-worth influenced by bodyweight or shape, or persistent lack of recognition of seriousness of low bodyweight | |
| D) Refusal to maintain body weight over a minimal normal weight for age and height | D) In menstruating females, absence of at least 3 consecutive non-synthetically induced menstrual cycles | |
| E) No known physical illness that would account for weight loss | Specify Type: | Specified Whether: |
| | Restricting type: During the current episode, has not regularly engaged in binge eating or purging | Restricting type: During the last 3 months has not regularly engaged in binge eating or purging |
| | Binge-eating/ purging type: During the current episode has regularly engaged in binge-eating or purging | Binge-eating/purging type: During the last 3 months has regularly engaged in binge-eating or purging |
| | | Remission:<br>Partial remission: After full criteria met, low bodyweight has not been met for sustained period, BUT at least one of the following two criteria still met: intense fear of gaining weight/ becoming obese or behavior that interferes with weight gain<br>OR<br>Disturbed by weight and shape<br>Full remission: After full criteria met, none of the criteria met for sustained period of time. |

Table 1: Comparing DSM diagnosis of Anorexia Nervosa (American Psychological Association 1980, 1994, 2013).

Appendix C Recruitment Poster

# *Have you received a NG tube in your treatment for Anorexia ?*

WE WANT TO HEAR YOUR EXPERIENCE

## *Study Brief*

We are currently looking for women who have received nasogastric feeding as part of their inpatient treatment for Anorexia

## *Participant Criteria*

- Women who are aged 18-years or older
- Received a nasogastric tube as part of your treatment
- Have not been inpatient, hospitalised or in residential treatment for your eating disorder since October 2017
- Consider yourself to be in a stable place of recovery

## *Contact Rhiannon at*

Email:
rhiannon.lehndorfmoore@hotmail.co.nz
Mobile: 021-114-0261

# Appendix D Meta-Ethnography Brief

Currently there are no reviews that specifically examine the patients lived experience of inpatient treatment for anorexia nervosa. Utilising Noblit and Hare (1988) steps for a meta-ethnography the research question "What is the patient experience of inpatient treatment for Anorexia Nervosa was developed". After developing the research question a systemic search was conducted searching the following databases: Psych INFO, Discover, Scopus, Web of Science, Health Databases on EbscoHost. As the target population for the study was those with anorexia nervosa the following search terms were used; Anorexia Nervosa, Anorexia, Anorexia and Eating Disorder. As the study was specifically interested in inpatient experiences the terms Inpatient, Hospitalisation, Hospitalization and Treatment were used. Finally, as I was interested in the lived experience, I used the terms Perspectives, Patient experience, Patient view and Patient perception.

The search term yielded 345 articles, after reading the titles and abstracts of each article 314 were excluded. This resulted in 31 articles, the 31 articles were then examined and read to see if they meet the criteria. The articles were then read a second time. After excluding articles that did not meet the criteria for the review this left 10 suitable articles.

The articles were then read again, and primary themes and concepts were developed for each article and then secondary themes were identified. Once each article had been analysed the primary themes and concepts as well as secondary themes for each article were compared against one another. After competing this step, I identified how the articles related to each other and the differences between them.

This resulted in the development of how the studies related to each other. 10 primary themes then resulted from the study. These themes were then synthesised.

The primary and secondary themes are as followed; 1. Difficulty associated with accessing treatment 2. Desire for a therapeutic alliance 3. Inpatient treatment specifics 4. Lack of understanding from staff 5. Just another anorexic 6. Living in a bubble 7. Influence of peers 8. Treatment trauma 9. Treatment reproducing eating disorder behaviour and 10. Development halted.

# Appendix E Articles examined in meta-ethnography

| No. | Researchers | Year | Topic | Sample | Age (Years) | Data Analysis | Data Collection | Tx Status | Nationality | Journal |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Rance, Moller and Clarke | 2017 | Experiences of being treated for AN | 12 Females | 18-50 | Thematic Analysis | Semi structured interview | Primarily IP treated. | British | Journal of Health Psychology |
| 2 | Zugai, Stein-Parbury and Roche | 2013 | How nurses influence IP treatment. | 8 Females | 14-16 | Thematic Analysis | Semi structured interview | IP treatment | Australian | Journal of Clinical Nursing |
| 3 | De La Rie, Noordenbox, Donker and Furth | 2006 | Evaluating treatment of eating disorders from the patient's perspective | 304 Females | Mean age 28.7 +/- 8.9 | Thematic Analysis | Mixed Methods | Mixed IP and OP | Dutch | International Journal of Eating Disorders |
| 4 | Sherldan and McArdle | 2016 | Exploring patients' perspectives of IP treatment | 11 Females | 18-31 | Interpretive Thematic Analysis | Semi structured interview | IP treatment | Irish | Qualitative Health Research |
| 5 | Strand, Bulik, Hausswolff-Juhlin and Gustafsson | 2016 | Exploring patients' experience of participating in a self-admission to IP program | 15 Females and 1 Male | 18-56 | Content Analysis | Semi structured interview | IP treatment | Swedish | International Journal of Eating Disorders |
| 6 | Smith et al | 2016 | Exploring experiences of women currently undergoing IP treatment for AN | 21 Women | 18-41 | Thematic Analysis | Semi structured interview | IP treatment | Scottish | Journal of Health Psychology |
| 7 | Offord, Turner and Cooper | 2006 | A retrospective study exploring young adults' perspective of AN IP treatment | 7 Women | 16-23 | Interpretive Thematic Analysis | Semi structured interview | IP treatment | British | European Eating Disorder Review |
| 8 | Colton and Pistrang | 2004 | Adolescents' experiences of IP for AN | 19 Women | 12-17 | Interpretive Thematic Analysis | Semi structured interview | IP treatment | British | European Eating Disorder Review |
| 9 | Fox and Diab | 2015 | Experiences of IP treatment for those with Chronic AN | 6 Women | 19-50 | Interpretive Thematic Analysis | Semi structured interview | IP treatment | British | Journal of Health Psychology |
| 10 | Wu and Harrison | 2019 | Exploring IP treatment experience for AN | 4 Women | 16-19 | Interpretive Thematic Analysis | Semi structured interview | IP treatment | Chinese | Journal of Eating Disorders |
| | | | | | | | | | British | Counselling and Psychotherapy Research |

# Appendix F Interview Guide

The interview guide will provide a brief overview of the interview process. The interview process is semi-structured and thus the participants will have a lot of control over the direction the interview will take. The interview will take place in ideally a conversational manner and there may be some diversion to the interview questions dependent on the participant's answers.

[Research Question: provide an understanding of how anorectic women experience treatment to improve health care experiences. This research has two objectives, namely:

a. To explore the narratives of recovered anorectic women who received a nasogastric tube as part of their treatment, and
b. To examine how nasogastric tubes influenced the women's illness identity with Anorexia Nervosa. ]

Following Tikanga Maori values, the start of the interview will be focused on the value Whanaungtanga. Whanaungtanga translates to a sense of belonging. Therefore, at the start of the interview, the participant and I will spend some time getting to know each other. Dependent on the culture of the individual this may involve sharing of a Pepeha or alternatively some casual talking. This will be done to help facilitate a connection and allow the participant to be relaxed.

**Interview Questions**

1. Did you find having the nasogastric tube changed your relationship with Anorexia Nervosa?

2. Did having the tube, which is a medical piece of equipment, make you look at anorexia nervosa differently?
3. How did you manage having a nasogastric tube?
4. What did you think once you had a nasogastric tube?
5. Did you find people treated you differently once you had the tube?
6. Do you agree with the decision to tube you?
7. How did you find the medical process involved with nasogastric tubing?
8. Did you think at the time the tube would help with your recovery?
9. Do you think the ng tube shaped your recovery differently?
10. Is there anything else you would like to add, or anything else you would like me to know?

# Appendix G  Helpline Numbers

If this interview has brought up anything distressing or triggering, and you need someone to talk to, the following services offer free support.

National Helplines

Lifeline:

Phone 0800-543-354 or free text 4357

Availability 24/7

Suicide Crisis Helpline:

Phone 0508-828-865

Availability 24/7

Healthline:

Phone 0800-611-116

Availability 24/7

Community Mental Health Crisis 24 hour service:

Phone 0800-800-717

Availability 24/7

Butterfly Foundation National Helpline:

Phone:  00-64-1800-334-673

Email: support@thebutterflyfoundation.org.au

Availability: 8am-12am, closed national public holidays, Christmas Day, Boxing day and New Years Day.

Need to Talk ?:

Phone: 1737

Availability: 24/7

# Appendix H Ethics Approval

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 30 October 2019

Dear Rhiannon Lehndorf Moore

Re: Ethics Notification - **NOR 19/51 - Adult women's' experience of nasogastric feeding in the context of Anorexia Nervosa.**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Northern Committee** at their meeting held on **Wednesday, 30 October.**

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

**Research Ethics Office, Research and Enterprise**
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 350 5573; 06 350 5575 **F** 06 355 7973
**E** humanethics@massey.ac.nz **W** http://humanethics.massey.ac.nz

# Appendix I Information Sheet

***Exploring nasogastric tube experiences in inpatient treatment for Anorexia Nervosa***

My name is Rhiannon Lehndorf Moore and as part of my Masters of Science in Health Psychology. I am doing some research on exploring women's experiences with nasogastric tubes in the context of inpatient treatment for Anorexia Nervosa.

You are invited to take part in this study. Whether you decide to take part or not is your choice. If you do not want to take part, you do not have to give a reason.

This Information Sheet will help you decide if you want to participate in this study. It outlines why I am doing the study, what involvement is needed from you if you wish to participate, any benefits or risks there may be, and what would happen at the conclusion of the study. You do not have to decide immediately whether you would or would not like to participate in this study. Before you decide, you may want to discuss the study with other people, such as family, whānau, friends, or health providers, and you may and are encouraged to do so.

This Information Sheet is three pages long. Please take the time to read and understand all the pages of the Information Sheet before providing consent. If you agree to take part in this study, you will be asked to sign a consent form.

**Who can participate in this project?**

This research is aiming to examine the experiences of women who have received a nasogastric tube (NG) during inpatient treatment for Anorexia Nervosa. This research is aiming to give participants a voice for an area of anorexia treatment that is often overlooked. You will be invited to share your experiences using an in-depth interview and are welcome to bring in any photos/journals/ diaries that you kept during your inpatient treatment.

*Inclusion Criteria*

- Women who are aged eighteen years or older
- Have received a diagnosis of Anorexia Nervosa (Atypical, Or Restrictive Or Binge/ Purge subtype).
- Received a nasogastric tube as part of your treatment

- Have not been inpatient, hospitalized or in residential treatment for your eating disorder since October 2017
- Currently not receiving treatment from regional eating disorder services
- Consider yourself to be in a stable place of recovery
- Can speak English fluently

Women of any ethnicity are invited to participate however, the interviews will be conducted in English. I reside in Auckland so face-to-face interviews will be conducted in Auckland, but participants can reside anywhere in New Zealand if you are happy be interviewed on the phone or via skype.

**If you participate what will you be required to do?**

If you decide to participate in this study, you will be asked to participate in one semi-structured in person or via skype. The interview should take around one hour to complete. You are free to withdraw from the research at any time during data collection. You may bring whanau, friends or other support people to your interviews.

The interview will be semi-structured, where you will be given a couple of prompt questions, however, the interview will be dictated primarily by you and how much you chose to share. The interview will be audio recorded and transcribed by the researcher to inform data analysis. After each interview has been transcribed, the transcription will be sent to you, as this is a collaborative process, so if you would like something changed, or you would like to add something you will have the opportunity to do so.

Participants are also offered the opportunity to bring in any pictures, diaries, blog entries, Instagram posts that they wrote/created during their inpatient treatment, that they would like to share. With your permission, these will be photographed and used to assist the understanding of your treatment experience. If you wish I will return your transcribed interview script to you for comment. Participants will be given a $25NZD gift card as an acknowledgment of their time and for their participation.

There is no anticipated harm or discomfort intended as part of this research, however I do acknowledge that living with Anorexia Nervosa has many challenges and treatment is not an easy process. I am interested in your inpatient experiences with a particular focus the NG experience as there is limited research and voice given to women in inpatient settings

or discussion around the use of NG tubes. You will not have to discuss anything you do not wish to and we will go at a pace which feels most comfortable for you. We can take breaks throughout the process. If at any time you feel uncomfortable with a question, you can choose not to answer the question and we will proceed onto the next question.

**Data Management**

The information/data that you provide in each interview will be recorded on a voice recorder and will initially only be accessible by the researcher and supervisors directly involved in this study. Once the information has been transcribed (put into written form) for each interview, you will be provided with a copy of these transcriptions, which you may edit and make adjustments to if you feel necessary.

After you have read through each transcript, a Transcript Release Authority Form will be provided for you to sign if you wish, allowing the researcher to use the information from the transcription, as by signing you will be indicating that you accept the transcript and the usage of such.

Once the verbal information has been transcribed it will then be coded for themes and ideas present throughout the interview. All identifying information will be removed from the transcript, the data, and the write-up of the research, in order to ensure that it is not possible for you to be identified. The qualitative data gained from the interview will only be accessible by the researcher and supervisor initially, however, there is the possibility that your responses may be used in research publications.

Any personally identifying information that you provide will be stored on a password-protected computer and hard-drive until the research is complete at the end of 2020, and then it will be deleted. However, a deidentified (anonymous) form of your transcript and the coding which will not include any identifying information (e.g. names, places, dates, etc.) will be stored indefinitely in Massey H drive, as the data saved to Massey University's network as it is the most secure place to keep any data as it is secure and backed up.

A summary of the project's findings will be available once the project is complete in end of 2020. I will send this to you if you request this.

**Participant's Rights**

*You are under no obligation to accept this invitation. If you decide to participate, you have the right to:*

- *Decline to answer any particular question;*
- *Withdraw from the study at any time during the data collection;*
- *Ask any questions about the study at any time during participation;*
- *Provide information on the understanding that your name will not be used;*
- *Be given access to a summary of the project findings when it is concluded.*
- *Ask for the recorder to be turned off at any time during the interview*

**Project Contacts**

You are invited to contact either the researcher or supervisor if you have any questions about the study.

*Researcher:*
Rhiannon Lehndorf Moore

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*This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 19/51. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Committee Chair), Massey University Human Ethics Committee: Northern, email* humanethicsnorth@massey.ac.nz.

# Appendix J Consent Sheet


***Exploring nasogastric tube experiences in inpatient treatment for Anorexia Nervosa***

**PARTICIPANT CONSENT FORM - INDIVIDUAL**

I have read, or have had read to me in my first language, and I understand the Information Sheet attached as Appendix I. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study during data collection.

1. I agree/do not agree to the interview being sound recorded.
2. I wish/do not wish to have my recordings returned to me.
3. I agree to participate in this study under the conditions set out in the Information Sheet.
4. I wish/do not wish to have my transcripts returned to me

**Declaration by Participant:**

I _____ hereby consent to take part in this study.

**Signature:** _____ Date: _____

If you have requested a summary of the research findings or to have your recordings returned to you for editing, please provide contact information below
Please provide either your address or email address below.

Address : _____